DOCUMENT RESUME

ED 305 807 EC 212 758

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|---|---|
| AUTHOR | Hughes, M. Jeffry; Segall, Alexander |
| TITLE | Community Adjustment of Former Residents of the Manitoba Development Centre. Final Report. |
| INSTITUTION | Manitoba Univ., Winnipeg. Dept. of Educational Psychology.; Manitoba Univ., Winnipeg. Dept. of Sociology. |
| SPONS AGENCY | Department of National Health and Welfare, Ottawa (Ontario). National Welfare Grants. |
| PUB DATE | Aug 88 |
| NOTE | 130p. |
| PUB TYPE | Reports - Research/Technical (143) |
| EDRS PRICE | MF01/PC06 Plus Postage. |
| DESCRIPTORS | *Adjustment (to Environment); Community Programs; Daily Living Skills; *Deinstitutionalization (of Disabled); Group Homes; Institutionalized Persons; *Mental Retardation; *Normalization (Handicapped); Performance Factors; *Predictor Variables; Quality of Life; Residential Programs; *Social Adjustment |
| IDENTIFIERS | Attitudes Toward Disabled; *Independent Living; Manitoba; Manitoba Development Centre; Neighbor Attitudes |

ABSTRACT

This study investigated the community adjustment of individuals with mental retardation who were former residents of the Manitoba Development Centre (MDC) in Canada. The study explored the combined effects of personal factors, residential factors, and neighborhood attitudes on community adjustment, to identify the best set of predictors of community adjustment. The study focused on 91 former residents of the MDC who were released from the institution and who were living in the community at the time of the sampling, and 24 residents who were released but subsequently returned to live in the institution. Data were collected from MDC files; surveys of subjects, mental retardation workers, and 243 neighbors of community residents; and participant observation techniques with the community sample. Findings concerning the community sample include: (1) most (79%) lived in community residential facilities with paid staff, while a few lived independently or with parents; (2) virtually no community subjects participated in organized recreational activities with the non-handicapped in the community; (3) 74% were working, almost all in some kind of sheltered employment; (4) overall attitudes of the neighbors were quite positive; and (5) quality of life was quite satisfactory. Predictors determining community living or reinstitutionalization were the availability of a helper, subject's independent living skills, number of times re-admitted to the MDC, and behavior rating by the residential supervisor. (JDD)

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# COMMUNITY ADJUSTMENT OF FORMER RESIDENTS OF THE MANITOBA DEVELOPMENT CENTRE

(Project Number 4556-29-4)

Final Report
August, 1988

Submitted to:

National Welfare Grants Program
Health and Welfare Canada
Ottawa, Ontario

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## ACKNOWLEDGEMENTS

This research was supported by a grant from the National Welfare Grants Program, Health and Welfare Canada, Ottawa, Ontario (Project number 4556-29-4).

There are many people to thank for their assistance in carrying out this province-wide survey. First of all, the staff at the Manitoba Development Centre assisted in the review of file data necessary for drawing the sample for this study. The staff also facilitated the interviews which were conducted at the Manitoba Development Centre.

In addition, the provincial government Department of Community Services and Department of Health, as well as the Office of the Public Trustee, contributed to the success of this project. In particular, Community Services Regional Directors and program staff (e.g., MR coordinators and workers) played a vital role in locating and contacting the subjects to be interviewed throughout the province.

Ms. Valerie Michaud served as the Project Director and did an excellent job of supervising the fieldwork stage of the research. She was responsible for ensuring that the sample lists were accurate, deploying interviewers and monitoring the quality of the data collected. The project was fortunate to be able to employ a group of experienced and highly capable interviewers. Mr. Daniel O'Connor must also be acknowledged for his data management skills and for assisting with the statistical analysis.

The Social Sciences Division of University of Manitoba Research Ltd. (formerly the Institute for Social and Economic Research) provided administrative and technical support for the project.

Last, but certainly not least, the project is indebted to the subjects who provided the requested information. Without their willing cooperation, the research would obviously not have been possible.

While the successful completion of this type of study invariably involves the time and talents of many different individuals, the views expressed in this report are the sole responsibility of the co-authors.

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# CHAPTER 1 - INTRODUCTION

## 1.1 DEINSTITUTIONALIZATION AND THE MENTALLY RETARDED

The policy of deinstitutionalization has its origins in the "Principle of Normalization". Advocates of this policy have been active in demanding the dismantling of the system of state operated institutions because of their regimentation, restriction of personal liberty, denial of independence and personal choice, and their general dehumanizing effects on the residents (Wolfensberger, 1972; Blatt & Kaplan, 1966; Bilken, 1979). These criticisms derive from a complex set of circumstances which developed from the belief of those who originally designed the institutions that the welfare of the residents and the community at large would best be served by large institutions set in grounds remote from populated centres. These beliefs have been seriously challenged by the "Principle of Normalization" which states that there should be utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible (Wolfensberger, 1972). The assumption has been made by the most ardent of supporters of deinstitutionalization that the least restrictive environment is provided by some form of community residential facility, rather than by a large institution. It is further assumed by these advocates, that community facilities will provide greater emphasis on freedom of choice, individuality, independence and a better opportunity for community integration. However, these assumptions have not been

extensively investigated in Canada and it remains to be established that community residential facilities provide the opportunities for community integration and an enhanced quality of life.

The earliest efforts to investigate the ability of the retarded to function in the community took the form of a search for client characteristics which best predicted success. The search produced much contradictory evidence and failed to identify factors which were consistently associated with successful community adjustment. Later efforts focused on the social service system and the relationship between individual characteristics and environmental factors (Lakin, Bruininks & Sigford, 1981). Descriptive statistics reported in these studies emphasized system and individual variables as factors influencing community adjustment and although several factors, such as the role of benefactors, appear relevant, the evidence is not consistent across all environments and with all categories of the retarded population. However, there are suggestions from several sources that a range of environments should be provided to accommodate the varying abilities and needs of the population (Gollay, 1981). These conceptions of the relationship between individual and environmental characteristics emphasize that success in community adjustment is a relative concept. The outcome depends on the way in which success is defined and measured, and on the demands placed on the individual by a specific environment. Success can be structured by adjusting the demands of the environment to the competency of the individual (Intagliata, Willer & Wicks, 1981). This conception of the relationship between personal and environmental

characteristics would appear to have particular relevance to the mentally retarded, among whom there is a great variation in individual need and ability to cope with the demands of specific environments.

In addition to individual and environmental characteristics, there is growing awareness that community attitudes toward the retarded and toward community residences for the retarded are important factors influencing the success of the deinstitutionalization movement. Gottlieb (1975) suggests that much of the opposition to community residences is due to a negative view of the retarded held by the public which stems from public misconceptions about retardation. It is clear that public attitudes toward community residences will increase in importance as a treatment factor, as service delivery shifts from the institution to the community.

Many advocates of deinstitutionalization express satisfaction at the statistics indicating the discharge of many thousands of residents of state run institutions across North America. The satisfaction expressed appears to stem from the belief that any place is better for a retarded person than an institution. However, the satisfaction at the progress of this movement appears to ignore two important issues. Firstly, the high rate of recidivism reported in earlier studies (Freedman, Gollay & Wyngaarden, 1976; McCarver & Craig, 1974), and secondly, the appalling conditions under which many people are forced to live upon discharge (Edgerton, 1967). A concern over recidivism rates continues although the issue is a complex one in which the cause of return to the institution needs investigation as it does not always signal a failure to adjust on

the part of the individual, but rather a failure of the community to provide the appropriate conditions for the individual.

The issue of quality of life is equally complex, although there is some consistency among writers in equating quality of life with the principles of normalization (Balla, 1976; Bradley, 1978; Peck,, Blackburn & Blackburn-White, 1980). Factors identified as relevant to the issue of quality of life include: the extent of integration into the community (Intagliata, Crosby & Neider, 1981; the availability of benefactors to assist in time of need (Edgerton & Bercovici, 1976; Wyngaarden, 1976); the important role of staff in providing appropriate social skill and vocational training (Birenbaum & Seiffer, 1976); and being part of a co-operative social group for lifestyle planning (Obrien, 1985). Although efforts have been made to identify objective measures of quality of life, Edgerton & Bercovici (1976) and Scheereneberger (1976) consider consumer satisfaction to be the single most important measure of quality of life. Despite the difficulty in obtaining accurate and valid information from mentally retarded subjects, it is essential that their personal views be considered because it is important to know how they perceive their own current life-style.

## 1.2 OBJECTIVES OF THE STUDY

The primary purpose of this study was to investigate the community adjustment of former residents of the Manitoba Development Centre. For the purposes of this research, community adjustment was defined as comprising: (a) the degree of community integration (reflected by

factors such as the size and composition of the individual's social network, and the number of times reinstitutionalized); and (b) the quality of life experienced by the deinstitutionalized mentally retarded living in the community (indicated by the degree of personal satisfaction expressed about the individual's self-reported ability to function independently in the community). The study explored the combined effects of personal factors, residential factors and neighbourhood attitudes on the community adjustment of former residents of the Manitoba Development Centre. The ultimate objective of the research was to identify the best set of predictors of community adjustment, and thus provide an empirical data base which could be used to create the type of circumstances most likely to result in effective re-entry into the community by deinstitutionalized mentally retarded persons.

## CHAPTER 2 - RESEARCH METHODS

To learn more about the factors which influence successful community adjustment, the present study focused upon two groups of mentally retarded people in Manitoba: (1) former residents of the Manitoba Development Centre (MDC) who have been released from the institution and are currently living in the community (Community Sample); and (2) residents who were released from the Manitoba Development Centre (MDC), but have subsequently returned and are currently living in the institution (Reinstitutionalized Sample). The study was designed to explore the relative impact of personal, residential and neighbourhood factors on the community adjustment of former residents of this institution. In addition, an effort was made to identify the types of factors which account for differences between the mentally retarded who have successfully re-entered the community and those who have been reinstitutionalized.

### 2.1 SAMPLE SELECTION

In order to establish the sampling frame for the study, all of the admissions and discharges at the MDC since 1967 were reviewed. During July and August, 1985, approximately 1,000 available files were assessed. A number of inclusion/exclusion criteria were then applied to identify the parameters of the population of discharged mentally retarded persons to be sampled. The criteria used were:

(1) date of discharge - all those discharged between January 1, 1967 and December 31, 1984 were included.

(2) level of retardation - only mildly, moderately and severely retarded were included. All others were excluded as there are very few people in these categories (e.g., borderline, dull normal) still in the institution.

(3) length of institutionalization - temporary admissions and respite stay cases were excluded. All others were included if they had been residents at the MDC for a period of one year or more.

(4) type and location of residence - all those discharged to a community living arrangement were included (e.g., group home, foster home apartment). Those discharged or transferred to another institutional setting (such as the Pellican Lake Training Centre) were excluded. In addition, only those discharged to a community residence in the Winnipeg, Eastman, Westman, Central, Interlake and Parkland Health Regions of the Province of Manitoba were included (see Figure 2A). Those discharged to the Norman and Thompson Health Regions were excluded due to the small number involved and the high cost of contacting subjects in Northern Manitoba.

(5) completeness of information - only subjects for whom all required file data were available were included in the study.

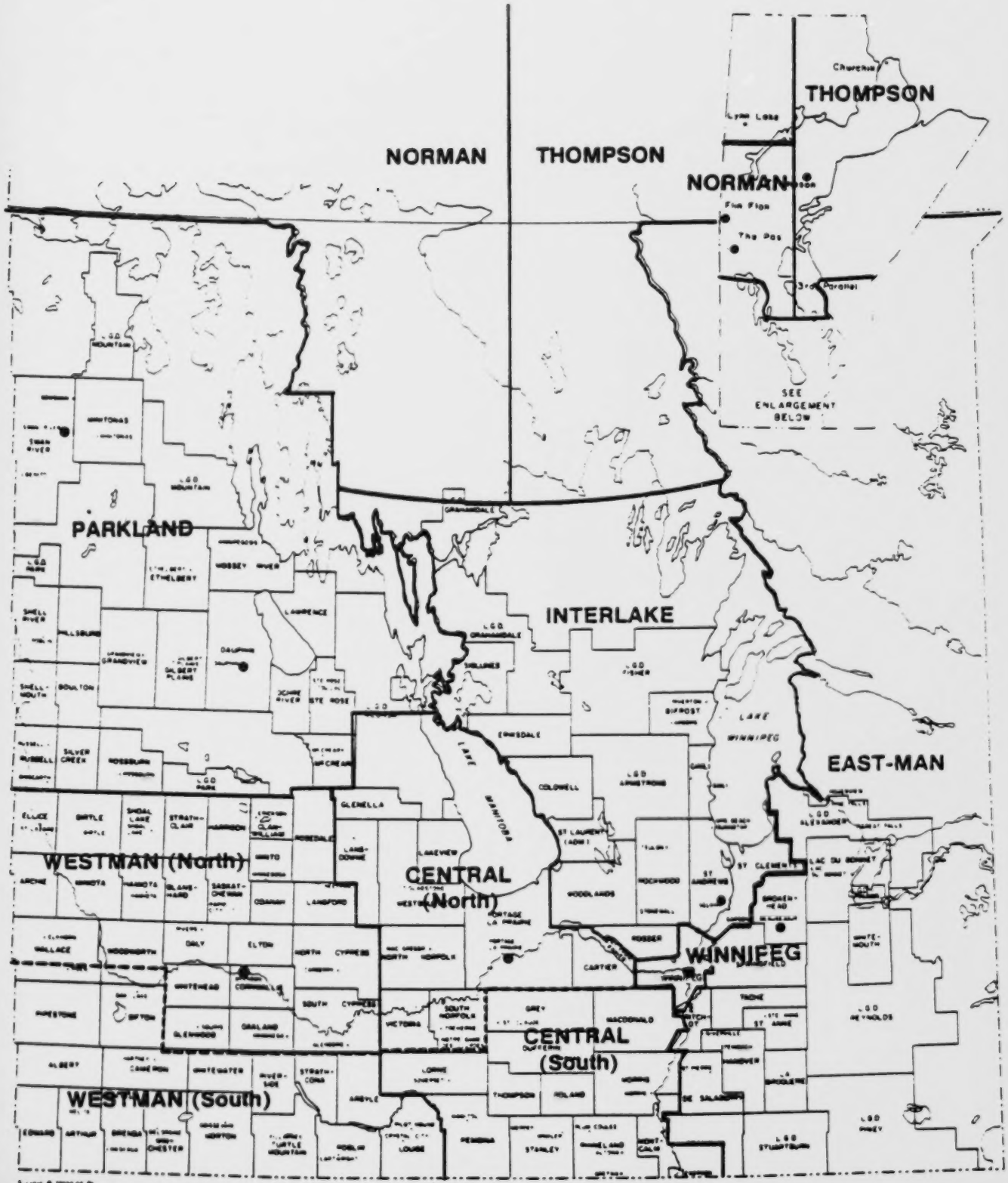
Once the population parameters had been identified and the inclusion criteria specified, the study made use of proportionate-to-size probability sampling techniques.

FIGURE 2A

# MANITOBA REGIONS

COMMUNITY SERVICES





2.1.1 Community Sample

Approximately 500 former residents of the MDC met the inclusion criteria for this study and were living in the community at the time the sample was selected. The discharged population currently living in the community was stratified in terms of: (a) level of retardation (mild, moderate and severe); (b) date of discharge (1967-1972, 1973-1978 and 1979-1984); and (c) Health Region (Winnipeg, Eastman, Westman, Central, Interlake and Parkland). A stratified random sample of 116 people was then drawn for data collection purposes. This procedure was used to ensure that the retarded persons included in the Community Sample are representative of the population from which they were selected. The identical procedure was used to draw an additional 116 names of former residents of the MDC living in the community. This substitution list was used to replace those in the Community Sample who could not be located (i.e., those who had moved out of the province, or who were deceased). Substitution, when necessary, was done by category (e.g., a moderately retarded person, discharged between 1979-1984 and living in the Interlake Region). During the fieldwork phase of the study, replacements were not made in the case of refusals. A total of ninety-one former residents of the Manitoba Development Centre currently living in communities throughout the province were interviewed (i.e., a response rate of 78 percent). This group constitutes the Community Sample (n=91).

2.1.2 Reinstitutionalized Sample

Approximately 120 residents have been readmitted to the MDC since

1975 and were still living in the institution at the time the sample was selected. The same inclusion/exclusion criteria used to define the discharged population were used for the reinstitutionalized population. For example, people who were living in the Norman or Thompson health Regions prior to readmission were excluded, as were residents who were transferred to MDC from another institution such as Pellican Lake or the Brandon Mental Health Centre. Seventy-eight residents met the inclusion criteria for the study and had been reinstitutionalized at the MDC after living for a period in the community. A stratified random sample of 30 people was then drawn for data collection purposes. Twenty-four of the mentally retarded persons who had returned to the MDC were interviewed (i.e., a response rate of 80 percent). This second group constitutes the Reinstitutionalized Sample (n=24).

## 2.2 DATA COLLECTION

In view of the complexity of the research problem under investigation, a multi-method approach to data collection was used. In other words, data were gathered from a variety of sources such as MDC files, mentally retarded persons living in the community and the MDC, and mental retardation workers.

To the extent possible, comparable data were collected for both the Community and Reinstitutionalized Samples. These data include:

(a) background information which was abstracted from MDC files for all subjects in both samples (e.g., age, sex, I.Q., dates admitted and discharged, type and location of residence);

(b) self-reported information about activities of daily living, interaction with family, friends and neighbours, work experience, use of transportation, and perceived quality of life which was collected by direct interviewing of all subjects in both samples; and

(c) corroborating data about life in the residence, performance in the work place, interaction patterns with co-residents and co-workers, and socioemotional behavioural problems which were gathered by interviewing Residential and Work Supervisors for members of the Community Sample, and by interviewing MDC workers for members of the Reinstitutionalized Sample.

In addition, further information was collected for the Community Sample only. These data include a neighbourhood attitude survey and interviewer ratings:

(a) public attitudes toward the mentally retarded were assessed by conducting a limited survey of the neighbours of each of the subjects in the Community Sample. Four households were randomly selected for each of the retarded persons interviewed, and an adult resident was asked to respond to a standardized social distance scale and provide some basic sociodemographic information. Data collected from neighbours were used to assess empirically community attitudes in terms of: public knowledge of retardation (cognitive component); feelings toward the mentally retarded (affective component); and how close a relationship with retarded people in the community they find acceptable (behavioural component); and

(b) finally, additional data were collected through participant

observation techniques. Interviewers spent a full day with each of the subjects in the Community Sample and kept extensive field notes in addition to completing the structured interviews. In this way, direct observational data were also collected (e.g., interviewer rated independent living skills, socioemotional behavioural problems, degree of integration, and quality of life).

In total then a great deal of information was collected about the community adjustment of mentally retarded persons in Manitoba. To summarize, the Community Sample data set includes: file and interview data for the 91 community living mentally retarded persons, as well as interviewer ratings and field notes for each subject. In addition, 86 Residential Supervisors and 69 Work Supervisors were interviewed. Finally, 243 neighbours were also interviewed (67% response rate). The Community Sample data were collected between January-April, 1986.

The Reinstitutionalized Sample data set includes: file and interview data for the 24 mentally retarded persons who had returned to the institution, as well as interviews with MDC workers for each subject. The Reinstitutionalized Sample data were collected in July-August, 1986.

Coding was done on an ongoing basis as the interviews in each of the regions of the province were completed. Once data entry and verification were finalized, all of the information collected from these different sources was then linked by subject to create a computerized set of data files for the purposes of statistical analysis.

## 2.3 STATISTICAL ANALYSIS

Data analysis was done in a number of successive stages. The first step was to compute descriptive statistics for all of the measures used in this study (i.e., frequency distributions, mean scores, standard deviation). Next, bivariate statistics were used. For example, a number of crosstabulations were run using Chi square tests to assess the strength and significance of the association between categorical variables such as sex, level of retardation, type of residence and community integration measures (e.g., type of transportation used). In addition, correlational analysis (Pearson r) was used in the case of continuous variables to assess the relationships: between various community integration measures (e.g., number of friends and times reinstitutionalized); and between different sources of information (e.g., self-rated and Residential Supervisor rated independent living skills).

In the final stage of the data analysis, multivariate statistics were used to assess the combined effect of a range of personal, residential and neighbourhood factors on community integration. Stepwise multiple regression was used to try to identify the best set of predictors of integration. In other words, of all the potential predictors measured which are the best at explaining variance in the dimensions of community integration under investigation (e.g., number of friends, familiarity with neighbours).

It should also be noted that varimax rotation factor analysis was used in constructing some of the scales used in this study (e.g., interviewer rated awareness and knowledge of money management,

housekeeping, etc). Cronbach's alpha was calculated for all scales to determine their reliability (e.g., Residential Supervisor and interviewer rated socioemotional behaviour). Additional information about each of these scales will be provided at appropriate points in the discussion of the findings.

The major findings of this study are organized in a manner which reflects the data analysis strategy. In other words, the discussion begins with descriptive information about the respondents, their living arrangements and life in the community and concludes with the amount of variance in social integration explained by the multiple regression analysis. However, not all of the aspects of community adjustment explored in this study were amenable to quantification (e.g., aspirations for an improved life in the community, perceived opportunities for independent decision-making). Consequently, subjects were asked a number of open-ended questions and their responses were recorded verbatim. For example - if you could change things about the way you live, what would you most like to change? Content analysis was performed on the responses to the open-ended questions, as well as the interviewers' detailed field notes. This information about the level of subjective satisfaction with life in the community found among the mentally retarded is intended to supplement the more rigorous statistical analysis of social integration and to provide greater insight into the quality of life of the mentally retarded in the community.

## CHAPTER 3 - THE COMMUNITY SAMPLE

### 3.1 REPRESENTATIVENESS OF THE SAMPLE

As described in the preceding research methods section, proportionate-to-size probability sampling was used in this study. This technique ensured that the initial Community Sample was representative of the population from which it was drawn. It is equally important to determine if the individuals actually interviewed are also representative of this population. Table 3A compares the initial stratified random sample (n=116) selected for data collection purposes and the former residents of the Manitoba Development Centre successfully interviewed (n=91).

**Table 3A**

**DISTRIBUTION OF COMMUNITY SAMPLE BY HEALTH REGION, LEVEL OF RETARDATION AND DATE OF DISCHARGE**

| | Stratified Random Sample | | Subjects Interviewed | |
|---|---|---|---|---|
| Health Region | N | % | N | % |
| Winnipeg | 45 | 39 | 30 | 33 |
| Central | 28 | 24 | 23 | 25 |
| Interlake | 7 | 6 | 6 | 7 |
| Westman | 11 | 10 | 9 | 10 |
| Eastman | 13 | 11 | 11 | 12 |
| Parkland | 12 | 10 | 12 | 13 |
| Total | 116 | 100 | 91 | 100 |

Table 3A continued

| | Stratified Random Sample | | Subjects Interviewed | |
|---|---|---|---|---|
| | N | % | N | % |
| **Level of Retardation** | | | | |
| Mild | 47 | 41 | 35 | 38 |
| Moderate | 52 | 45 | 47 | 52 |
| Severe | 17 | 14 | 9 | 10 |
| Total | 116 | 100 | 91 | 100 |
| **Date of Discharge** | | | | |
| 1967 - 1972 | 29 | 25 | 19 | 21 |
| 1973 - 1978 | 51 | 44 | 42 | 46 |
| 1979 - 1984 | 36 | 31 | 30 | 33 |
| Total | 116 | 100 | 91 | 100 |

Basically the Community Sample is quite representative of the population of discharged mentally retarded persons, who met the inclusion criteria for this study, in terms of health region, level of retardation and date of discharge. For example, in many regions of the province close to one hundred percent of the subjects were interviewed (e.g., Parkland, Interlake). The only notable exception was the Winnipeg region. In fact, Winnipeg is somewhat under-represented because of difficulties encountered in locating subjects and getting them to participate in the study.

Turning to level of retardation, it is interesting to note that both mild and severely retarded subjects are somewhat under-represented in the

final Community Sample (although probably for different reasons). In contrast, moderately retarded persons living in the community are over-represented in this study. Finally, the Community Sample is representative of the population in terms of date of last discharge. Only those discharged during the earliest time period studied (1967-1972) were slightly under-represented. It is not at all surprising that the study was more successful at locating and interviewing those who had been discharged from the Manitoba Development Centre in recent years.

## 3.2 SELECTED PERSONAL CHARACTERISTICS

Of the 91 subjects in the community sample, 40 (44%) were male and 51 (56%) were female. The age distribution for these subjects is reported in Table 3B. Participants in this survey ranged in age from 18 to 75 years. The mean was 42 years of age. The age distribution for this study is somewhat older than that reported in many similar types of studies, and may need to be considered in the interpretation of the results.

Table 3B

AGE DISTRIBUTION OF COMMUNITY SAMPLE

| Age Category | N | % |
|---|---|---|
| Under 20 | 1 | 1 |
| 21 - 30 | 19 | 21 |
| 31 - 40 | 28 | 31 |
| 41 - 50 | 18 | 20 |
| 51 - 60 | 13 | 14 |
| 61 and over | 12 | 13 |
| Total | 91 | 100 |

Mean = 41.7, Standard Deviation = 13.1

There was considerable variation in the institutional experience of the subjects in the community sample. As indicated by the data in Table 3C, the majority (73%) of the subjects were admitted to the MDC for the first time during the 1950's and 1960's. None had been discharged to the community prior to 1960. In fact, the most active period of deinstitutionalization in Manitoba was between 1970 and 1979.

The data in Table 3D indicate that 35 subjects had been in the MDC less than 10 years. A further 36 had been in the institution for between 10 and 19 years. The remaining subjects had been in the institution for more than 20 years, and the mean number of years was 13.7. A number (23) had been re-admitted to the MDC once, but very few (6) had been re-admitted more than once. Thus, the majority of the subjects had been discharged, for the last time, prior to 1980 and had not been readmitted to the MDC. In other words, they had been out in the community for a minimum of 6 uninterrupted years which should be ample time to integrate into community life.

Information about IQ was obtained for 69 of the subjects and ranged from a low of 35 to a high of 75 (with a mean of 53). All but 19 of the subjects remained under an Order of Supervision from the Public Trustee for the Province of Manitoba. Furthermore, all but 2 of the subjects were receiving social assistance from the government as their major source of income. A total of 57 (63%) had some type of physical disability, in addition to their mental retardation. Twenty-three of the subjects (25%) were identified by raters as displaying stereotypic behaviours sufficient to be noticeable at a first meeting. Fifty of the

subjects (55%) indicated they had received some type of training in the institution while the remainder were evenly split between those who had not received any training and those who did not know.

Table 3C

**DISTRIBUTION OF COMMUNITY SAMPLE BY DATE OF FIRST ADMISSION AND LAST DISCHARGE**

| Decade | First Admitted | | Last Discharged | |
|---|---|---|---|---|
| | N | % | N | % |
| 1930 - 1939 | 5 | 6 | 0 | 0 |
| 1940 - 1949 | 4 | 4 | 0 | 0 |
| 1950 - 1959 | 28 | 31 | 0 | 0 |
| 1960 - 1969 | 38 | 42 | 12 | 13 |
| 1970 - 1979 | 13 | 14 | 56 | 62 |
| 1980 - 1985 | 3 | 3 | 23 | 25 |
| Total | 91 | 100 | 91 | 100 |

Table 3D

**DISTRIBUTION OF COMMUNITY SAMPLE BY THE TOTAL NUMBER OF YEARS SPENT IN THE MANITOBA DEVELOPMENT CENTRE**

| Years in MDC | N | % |
|---|---|---|
| 4 or less | 18 | 20 |
| 5 - 9 | 17 | 19 |
| 10 - 14 | 21 | 23 |
| 15 - 19 | 15 | 17 |
| 20 - 24 | 10 | 11 |
| 25 - 29 | 1 | 1 |
| 30 - 34 | 5 | 5 |
| 35 - 39 | 0 | 0 |
| 40 - 44 | 3 | 3 |
| 45 - 49 | 0 | 0 |
| 50 or more | 1 | 1 |
| Total | 91 | 100 |

Mean = 13.7, Standard Deviation = 10.1

Subjects were asked if they had a helper (advocate) who assisted them with tasks to aid their living in the community. They were also asked to identify who this helper was (i.e., relationship to subject). Eighty percent of the subjects stated that they have someone in the community who helps them with difficult tasks. The data indicate that the number of family involved is low (9 or 10%), while the number of paid staff is high (54 or 59%). The average age of subjects (42 years), and the fact that they had spent many years in an institution (13 years) may help to explain the finding that family members were not actively involved in helping them maintain their community placement. A second factor to be taken into account is that many of those without helpers were the more severely handicapped for whom apparently, there was little expectation that they would be able to function in the community and therefore did not require that kind of assistance.

### 3.3 COMMUNITY LIVING ARRANGEMENTS

Information was also collected about the type and location of the residences in which subjects lived and the presence of supervisory personnel. Approximately one third of the subjects (30) were living in Winnipeg, with the remainder in towns (52) or on farms (9). The Winnipeg residents were divided between downtown (11) and suburban areas (19). Fifteen of the subjects reported they lived independently and four reported that they lived with their parents (Table 3E). The remainder (72 or 79%) lived in a residence with paid staff. The number of staff varied, but the majority lived with either one or two supervisors.

Table 3E

DISTRIBUTION OF COMMUNITY SAMPLE BY TYPE OF RESIDENCE

| Type of Residence | N | % |
|---|---|---|
| Parents home | 4 | 4 |
| Foster parents | 31 | 34 |
| House parents | 19 | 21 |
| Other supervised | 22 | 24 |
| Independent apartment | 10 | 11 |
| Other independent | 5 | 6 |
| Total | 91 | 100 |

The total number of residents and the number classified as mentally retarded is reported in detail in Table 3F. The detailed information is supplied because of the interest in size of residence and the fact that any type of summary may distort the information. The table indicates that subjects were distributed relatively evenly across residences with varying numbers of residents and with varying numbers of individuals classified as mentally retarded. Typically, subjects lived with five other people (four of whom are mentally retarded. Only 53 subjects (58%) reported that there is some type of transportation available to them at their residence.

## Table 3F

**DISTRIBUTION OF COMMUNITY SAMPLE BY THE TOTAL NUMBER AND THE NUMBER OF MENTALLY RETARDED CORESIDENTS LIVING WITH THE SUBJECT**

| Number of Coresidents | Total | | Mentally Retarded | |
|---|---|---|---|---|
| | N | % | N | % |
| 0 | 11 | 12 | 13 | 14 |
| 1 | 6 | 7 | 8 | 9 |
| 2 | 9 | 10 | 15 | 17 |
| 3 | 8 | 9 | 8 | 9 |
| 4 | 6 | 7 | 5 | 5 |
| 5 | 9 | 10 | 1 | 1 |
| 6 | 12 | 13 | 7 | 8 |
| 7 | 5 | 5 | 3 | 3 |
| 8 | 7 | 8 | 4 | 4 |
| 9 | 2 | 2 | 3 | 3 |
| 10 | 3 | 3 | 2 | 2 |
| 11 | 5 | 5 | 2 | 2 |
| 12 | 3 | 3 | 0 | 0 |
| 16 or more | 1 | 1 | 1 | 1 |
| No response | 2 | 2 | 6 | 7 |
| Don't know | 2 | 2 | 2 | 2 |
| Not applicable | 0 | 0 | 11 | 12 |
| Total | 91 | 100 | 91 | 100 |
| | Mean = 4.9, S.D. = 3.5 | | Mean = 3.7, S.D. = 3.5 | |

The mode of transportation available to residents is reported in Table 3G. The relatively high number of responses in the "not applicable" category includes those not living in supervised residences. The data indicate that only 20 individuals used public transport, while the remaining 33 individuals used some form of provided transport (e.g., van or car).

Table 3G

DISTRIBUTION OF COMMUNITY SAMPLE BY THE TYPE OF TRANSPORTATION AVAILABLE

| Type of Transportation | N | % |
|---|---|---|
| Public transportation | 20 | 22 |
| Handi-bus | 2 | 2 |
| Organization bus/van | 13 | 14 |
| Taxi - provided | 2 | 2 |
| Car - provided | 14 | 15 |
| Other | 2 | 2 |
| No response | 9 | 10 |
| Don't know | 1 | 1 |
| Not applicable | 28 | 31 |
| Total | 91 | 100 |

## 3.4 SUMMARY OF COMMUNITY SAMPLE CHARACTERISTICS

The community sample consists of a group of people with an average age of 42 years, who had spent an average of 14 years in the MDC. The institution files indicated the average IQ was 53, and that a small majority had received some kind of training prior to discharge. Almost all of the subjects were under an "Order of Supervision" from the Public Trustee and were receiving government social assistance. The majority had some kind of physical disability and one out of four displayed noticeable stereotypic behaviours. The subjects lived in residences of varying size located in urban, town and rural locations. Most of these residents depended upon "provided" transport to get around and only a small number used public transport. Most of the subjects indicated they had someone in the community who helped them with difficult tasks, but

generally these people were paid staff rather than family. Presumably, the relatively older age of the sample contributed somewhat to the low incidence of family support.

In reviewing the descriptive data, it was noticeable that there was a consistent pattern of use of the "no response" category. Closer investigation revealed that there was a core of eleven respondents who were unable, for a variety of reasons, to provide answers to the questions asked. All 11 were severely handicapped in verbal communication and also had a variety of physical problems (e.g., 3 were deaf). Only one member of this group worked, and not one was rated as capable of independent living. Most were reported to have virtually no friends other than an attachment to individual staff members and their only recreation was watching television in the residence. Thus, this group includes the most severely handicapped subjects in the sample who were described as requiring close and almost constant supervision.

As a consequence of this response pattern, interpretation of the data in many of the subsequent tables is cognizant of the fact that the "no response" category does not simply contain a random group of subjects who did not respond to specific questions, but a definable group of severely handicapped subjects. The limited communication skills possessed by this segment of the sample has important implications, not only for their participation in this survey, but also for their adjustment to life in the community.

# CHAPTER 4 - LIFE IN THE COMMUNITY: EVIDENCE OF INTEGRATION

## 4.1 RESIDENTIAL INTEGRATION

The data presented in the preceding chapter demonstrate that most of the subjects in the Community Sample (68%) lived in residences housing six or less individuals. A limited number (12) lived in residences with more than ten persons and these were generally elderly subjects who lived in personal care homes or a residence for the deaf. It should be noted that a similar number of subjects (11) lived alone. (These data are reported once again in the **Appendix - Table A1**, with the figures categorized to conform to the typical sizes of community residences).

Thus, most of the sample lived in residences with a limited number of other mentally handicapped people and a couple of non-handicapped co-residents who were generally staff personnel. Staff were defined, as those persons, including parents, who played a role in the supervision of the subject. The distribution of these non-handicapped co-residents is concentrated at the low end of the scale (i.e., one supervisor - 21%; two supervisors - 35%). The high percentage of those living with two staff reflects the proportion of foster and house parents caring for subjects in this sample. The fact that a small number of the subjects lived in rather large residential settings, such as personal care homes, accounts once again for the finding that some of the residences (9) had more than five staff members. Although most of these "staff" are in full-time residence with the subjects, some are only day staff or assist on a part-time basis.

Within the supervised residences most subjects (92% of valid responses) were expected to perform some type of household duties. These duties were described by the residential supervisors as either light (59%); moderate (36%) or heavy (5%). Light duties included personal care, while heavy duties included personal care and assisting with household chores both inside and outside the residence. The level of supervision exercised in the residences was described as either limited (34%); moderate (44%) or as extensive (22%). These figures would appear to reflect the wide variation in functional ability of the subjects in the sample, some of whom were described as requiring constant supervision for their own safety.

Relationships between the subjects and the residential supervisors were reported by the supervisors as fair (5%); good (48%); or very good (48%). These favourable opinions expressed by the supervisors appear to be endorsed by interviewers who in their field notes made generally favourable comments about the quality of supervision and the atmosphere in the supervised residences. Relationships between subjects and their co-residents were also viewed favourably by the residential supervisors. On a five point scale, (ranging from 1 - very poor to 5 - very good), the mean value was 4.2. No subject was rated as having a very poor relationship with others in the residence.

In response to questions about the most frequent activities they engage in at home in the evening, all but 11 subjects provided usable responses. The responses to this question ranged from the mundane "tidy my room" to the more exotic "liquid embroidery". However, the single

most frequent response (40 to 44%) was "watch TV". A similar question asked subjects to describe their most frequent activities on the weekend and holidays. Responses to this question varied a little from the previous question most noticeably in that subjects participated in more active recreation on the weekends or holidays. The data are summarized in Table 4A.

Table 4A

DISTRIBUTION OF COMMUNITY SAMPLE BY MOST FREQUENT ACTIVITIES AT HOME

| Type of Activity | Evenings | | Weekends | |
|---|---|---|---|---|
| | N | % | N | % |
| Household Chores | 25 | 27 | 20 | 22 |
| Passive Recreation (watch T.V.) | 40 | 44 | 31 | 34 |
| Active Recreation (play cards) | 5 | 6 | 20 | 22 |
| Creative Recreation (crafts) | 10 | 11 | 3 | 3 |
| Missing Data | 11 | 12 | 17 | 19 |
| Total | 91 | 100 | 91 | 100 |

## 4.2 COMMUNITY INTEGRATION

### 4.2.1 Presence

This dimension of social integration refers to the number and type of activities performed in the community (vs. at home). Subjects were

also asked to identify their most frequent activity when they go out of the residence in the evening or on weekends. The range of activities reported included: going shopping or out for coffee, and visiting friends and family. The younger and more athletic subjects reported engaging in more active pursuits such as bowling. A list of the most frequently reported activities is provided in Table 4B.

Table 4B

**DISTRIBUTION OF COMMUNITY SAMPLE BY MOST FREQUENT ACTIVITIES OUTSIDE THE RESIDENCE**

| Type of Activity | N | % |
|---|---|---|
| Going out to eat (coffee, lunch/dinner) | 19 | 21 |
| Active recreation (bowling, walking) | 19 | 21 |
| Shopping | 18 | 20 |
| Visiting Friends and Family | 9 | 10 |
| Passive recreation (movies) | 9 | 10 |
| Missing data | 17 | 18 |
| Total | 91 | 100 |

Frequency with which these activities were pursued varied with the type of activity reported and to some extent with the degree of independence of the respondent. Organized activities like bowling and some craft activities occurred on a weekly basis, whereas watching TV was reported on a more frequent basis.

4.2.2 Access

An additional factor to be taken into account in evaluating the extent to which subjects use facilities and services in the community is the type of transportation utilized. Subjects were therefore asked if transport was available to them from the residence. The results were reported earlier in Table 3G.

A follow-up question asked respondents to identify the type of transport they used when going out to social and recreational activities. The most striking feature of these data is that most respondents rely on, and use transport provided for them by some organization (40%) or walk (38%). Public transport is readily available to 22% of the respondents but is used only by 2% of them on a regular basis. The fact that a high proportion of the respondents walk to activities reflects the fact that some of these activities are conducted in parks near the residence or in other nearby facilities. A relatively high proportion (21%) have no transport available to them and an equal number provided no usable response to this question.

4.2.3 Participation

Subjects were asked questions about their participation in organized games and sports as a measure of community integration. A total of 35 (38%) responded that they played games in organized competition, but only 8 (9%) indicated that they played games organized for the non-retarded. However, an investigation of the actual responses provided by this subsample revealed that the level of organization involved in their games was extremely low. For example, several indicated they liked to go to

the park in the summer and play baseball with people in the park. Another indicated that he went to the park to play "horseshoes" with people he met there. In these cases, there was quite evidently no organization to formally arrange for games, but rather an informal arrangement whereby people from a residence were able to go to a nearby park and find local citizens willing to participate with them in informally organized recreation activities. Such an arrangement is admirable where the residence is conveniently located and the local population co-operative. On the other hand there was only one resident who participated in an activity that in any way could be described as resembling a regularly organized activity with non-retarded people. Of the 35 who indicated they played games, 26 felt they played the game well and an almost equal proportion stated they enjoyed playing the game. The way subjects rated themselves, as to ability, corresponded very closely with how they rated their enjoyment of this type of activity.

A second aspect of this dimension of community integration (i.e., participation) focused upon the nature of the subject's interaction with members of his/her social network (e.g., family, friends and neighbours). The subjects were asked if they had any family, to which 10 (11%) failed to reply and to which 7 (8%) replied "no". A large proportion of the subjects (74 or 81%) indicated they had family, but for most (43) family members resided in another town. Despite this, only a small proportion (17) reported they never or rarely visited with their family and all but 4 of the respondents reported they enjoyed these visits.

The subjects were also asked to indicate how many friends they felt

they had. Forty-three (47%) indicated they had many friends; while 34 (37%) indicated they had a few friends and only 3 (3%) indicated they had no friends. A total of 56 (77%) reported they see their friends frequently, and a similar number (58) reported they enjoyed visiting with these friends. Subjects were then asked how their friends thought about them. Using a three point scale, 8 (9%) responded they were viewed by their friends as an OK person; and 62 (68%) responded they were viewed as a nice person. No-one used the lowest value of the scale for their reply, but 23% of the responses provided no usable data. Subjects were then asked how many of their friends were not classified as mentally retarded. The data indicate that only 22 (24%) of subjects report having a non-retarded friend. If we were to assume that many of these recorded friends were in fact family members, the data do not indicate a high degree of social contact with the non-handicapped community for this sample.

Subjects were then asked a number of questions about their relationship with the opposite sex. A total of 36 (40%) stated that they had a boy/girl friend, although only 25 (27%) responded they enjoyed their visits with this person!

Finally, subjects were asked if they knew the names of their neighbours, to which 43 (47%) responded "yes". A high proportion of this group (33 or 77%) stated they spoke frequently with these neighbours, and a similar number (36) felt they talked often enough with these neighbours.

4.2.4 Production

Subjects were next asked about their work experience to learn more about their integration into the community. A high proportion (67 or 74%) reported they were currently working. Of the 15 who reported they were not currently working, 7 indicated that they previously had been employed since leaving the MDC. Thus, we can identify the remaining 8 subjects together with the 9 "no responses" who constitute a core of 17 (19%) who have no record of employment since leaving the institution. For the seven subjects who reported they had been employed, but were not currently working, the period of unemployment varied between 5 and 24 months with a mean of 12 months.

Data on the type of job setting for those reporting current or former employment is reported in Table 4C.

Table 4C

DISTRIBUTION OF COMMUNITY SAMPLE BY JOB LOCATION

| Present (Last) Job | N | % |
|---|---|---|
| Sheltered Workshop | 60 | 66 |
| Activity Centre | 5 | 6 |
| Warehouse | 1 | 1 |
| Store | 2 | 2 |
| Hospital | 2 | 2 |
| Farm | 1 | 1 |
| Car Lot | 2 | 2 |
| No response | 10 | 11 |
| Not applicable | 8 | 9 |
| Total | 91 | 100 |

These data reveal that a very high proportion (65 or 89%) of those working are employed in some form of sheltered environment. The type of duties were typical of sheltered employment with almost half of the sample reporting their tasks as sorting, packaging, assembly and woodworking operations. Only a very small number (8) were employed in some form of open employment situation. These data suggest that the subjects in this study are not well integrated into open employment, but rely heavily upon the provision of sheltered work opportunities. This view is further reinforced by the data on mode of transport to work, which once again indicates that only 18 subjects (20%) use public transport to get to work. The majority rely on provided transportation (34%) or walk (22%).

The total amount of time worked by subjects since their last discharge varies from 1 month to 20 years (mean = 9 years), with an even distribution across this time span. The number of jobs held by members of the sample since their last discharge from the MDC varied from 1 to 5 (mean = 1.9). Almost half of the valid responses (47%) indicated only 1 job, and a further 29% indicated 2 jobs. The number of hours worked per week also varied considerably with a range from 2 to 40 (mean = 34.4 hours). However, in this case, the distribution is uneven with 27 (41%) of valid responses indicating 35 hours of work and a further 23 (35%) indicating 40 hours of work per week. The amount of money earned by subjects also varied considerably with a range from no wages to $98/week (mean = $16.5).

The low level of remuneration for an average work week of

approximately 35 hours is explained by the fact that such a high proportion of those working are employed in sheltered workshops, where wages paid are traditionally extremely low. However, it should be recalled that 96% of the subjects reported they received social assistance as their major source of income. The low level of income received by the subjects constitutes a major limitation to their ability to participate in community activities.

Workers were asked if they enjoyed their job, to which 68 subjects (94% of valid responses) replied "yes" and only 4 subjects (6%) replied "no". When the subjects were asked to rate themselves on a 3 point scale on how well they did their job, their replies indicate that they rate their skills very highly (mean = 2.86). A total of 58 subjects said they did their job quite well. Subjects were also asked to rate (on a similar 3 point scale) how they felt their co-workers regarded them as workers. The mean score on this question was 2.9. Not unexpectedly perhaps, the ratings by subjects of how they feel they perform as workers and how they feel they are perceived as workers by their peers, were very similar.

Work supervisors also rated their relationship with the subjects on a five point scale ranging from very poor to very good. These ratings provided a relatively high mean of 4.2. In addition, work supervisors rated (on a similar scale) the relationship between the subjects and co-workers. These ratings were also quite high with a mean of 3.5. This corresponds with the subjects assessment of how many of their co-workers were their friends. The mean was 2.9 on a 4 point scale, with only 4 subjects replying they had "no friends". The high scores for friendship

among workers implies that the workshops provide an important source of social contacts for their employees.

Finally, subjects were asked if they had received any work training since their discharge from the MDC. The small number of affirmative responses (14 or 15%) would appear to indicate a serious lack of work training for this group of individuals. However, the subjects did not consider the work in the workshop to be training, whereas many supervisors would claim that the workshops provided training in work attitudes and in work skills.

4.2.5 Consumption

Turning to the last dimension of social integration, the ability of these subjects to manage their own money and to budget was generally quite poor. In fact, many stated that they are very poor at money management (8); can't manage at all (14); or that this task is done by someone else (24). Only approximately one-third of the sample (35%) felt they were able to look after their own money for shopping and paying bills.

Interviewers were also asked to rate subjects on their knowledge and awareness of money, budgeting and shopping. There appears to be a consistent assessment of subjects' abilities suggesting that more than half the sample can shop only with help; generally make only minor purchases; and have little knowledge of budgeting. By contrast, the number of subjects who are reported to be functioning well in each of these areas is quite small ranging from 12 (13%) to 16 (18%). These data suggest that there are few in this sample who have the money and

budgeting skills normally required of those who are able to function independently in the community. It appears that more than half the subjects were not capable of managing their own financial affairs and would require ongoing assistance to maintain an independent existence in a community setting.

## 4.3 SUMMARY OF RESIDENTIAL AND COMMUNITY INTEGRATION

In summary, most of the sample live in supervised residences with a small number of other mentally handicapped people and one or two paid staff to supervise and assist. Relationships within the residences were reported as very good and residents were expected to perform some type of light duties. The degree of supervision exercised by staff appeared to be related to the needs of the residents as indicated by their functional ability. Data on integration into the community may be interpreted as indicating that outside of the immediate family, there was minimal contact with individuals and agencies other than those organized by residence staff. In particular, few of the respondents reported having social contacts with non-handicapped people. Access to community services did not appear to be a major problem, however, most of the sample made little use of such services, and when they did almost all of the subjects relied upon some form of provided transportation.

Although a high proportion of the sample (74%) report that they are working, the majority of these people work in sheltered workshops and receive both minimal income and limited additional training. However, it should be noted that relationships between subjects, work supervisors and

co-workers were described in very positive terms.

Turning to consumption skills, the subjects in this survey were not very competent at money management. Few of the sample were capable enough to engage in anything more than the purchase of small items and were certainly not capable of managing their own monetary affairs. However, it must also be pointed out that few of the subjects had access to money and the amount of disposable income available for discretionary purchases was very limited. Consequently, practical opportunities for money management were also extremely limited.

# CHAPTER 5 - INDEPENDENT LIVING SKILLS AND COMMUNITY INTEGRATION

## 5.1 INTRODUCTION

The move toward community placement of former residents of institutions for the mentally retarded has resulted in an increased awareness of the importance of the skills required by those who wish to live independently and function competently in society. These independent living skills have become a major focus both of training programs and assessment instruments and occupy a central role in the planning for community integration of the retarded. The value of increasing the competence of the retarded in these skills is difficult to dispute. However, the necessity of these skills for successful integration has been obscured by a lack of clarity in defining integration and a tendency to overlook the criteria for success, especially with regard to the different levels of competency exhibited by those with differing degrees of mental handicap.

## 5.2 SUBJECTIVE ASSESSMENT

All subjects in the Community Sample were asked a general question about how well they think they are managing overall at living in the community. The responses to this question are summarized in Table 5A. Most respondents who answered this question stated that they are managing fairly well (26) or quite well (31). Only 4% felt that they were doing very poorly or could not manage at all. In addition, it is important to note that one third of the subjects did not respond or stated that they did not know the answer to this question.

**Table 5A**

**SUBJECT ASSESSED ABILITY TO MANAGE LIVING IN THE COMMUNITY**

| Response Category | N | % |
|---|---|---|
| Can't manage at all | 3 | 3 |
| Very poorly | 1 | 1 |
| Fairly well | 26 | 29 |
| Quite well | 31 | 34 |
| No response | 18 | 20 |
| Don't know | 12 | 13 |
| Total | 91 | 100 |

To gain a more detailed understanding of self-rated independent living skills, the subjects were also asked a number of specific questions to determine their self-assessed ability to look after themselves in the community. All of the participants in the survey were asked to respond to the following five questions: How good are you at washing your clothes? How good are you at dressing yourself? How good are you at keeping your room clean and tidy? How well do you do in preparing things to eat for yourself? How well do you look after money, for shopping and paying bills? The response categories for these questions included: I don't manage at all (1); I am very poor at it (2); I am fairly good at it (3); and I am very good at it (4). In addition, don't know, not applicable (i.e., done by someone else) and no response categories were also provided. Overall, respondents varied considerably in the way they described their independent living skills. On the positive side, they stated that they are good at dressing (81%) and taking care of their own room (80%); compared to preparing food (44%),

washing clothes (38%) and managing money (36%). Actual responses to these items are summarized in the Appendix in Table A2.

To explore potential sources of variation in these self-reported independent living skills, cross-tabulations were run using each of these behavioural items as a dependent variable. The independent variables selected included: level of retardation, respondents' sex, education/training, total number of years spent in the institution and number of people living in the community residence. With only one exception, none of the relationships examined was found to be statistically significant (i.e., $p<.05$). The only significant relationship found was between sex and money management ($p=.05$, gamma= -0.49). In other words, male subjects felt that they do much better, than female subjects, at looking after money.

Correlations between the five self-reported independent living skills items varied from moderate ($r=.30$) to strong ($r=.70$). These five items were combined to form the Subject Independent Living Skills Scale (ILSCALE). Corrected item-total correlation coefficients range between .46 and .77 and these items form a reliable additive scale (i.e., Cronbach's alpha = .82). In computing Subject Independent Living Skill Scale scores, means were assigned by case for missing values if a minimum of three of the five questions were answered. Scores on this scale ranged from 5 (poor) to 15 (good skills) and the mean score was 11.77 (standard deviation = 2.72). The relationship between scores on the Independent Living Skill Scale and measures of community integration will be explored in a subsequent chapter.

## 5.3 EVALUATION BY OTHERS

An evaluation of how subjects were functioning in terms of their independent living skills and community integration was provided by residential and work supervisors and by interviewers' ratings.

### 5.3.1 Self and Interviewer Rated Living Skills

In an effort to examine the validity of the subjects' self-assessed independent living skills, their responses were compared to interviewers' ratings on five similar items. The interviewers rated each subject on a number of dimensions including: laundry (does not do own laundry, does poor job, does reasonable job and does good job); dressing; care of own room; meal preparation; and use of money.

**Table 5B**

**CORRELATION BETWEEN SELF-RATED AND INTERVIEWER RATED INDEPENDENT LIVING SKILLS**

| | Interviewer Ratings | | | | |
|---|---|---|---|---|---|
| Subject Ratings | Laundry | Dressing | Bedroom | Meals | Money |
| Wash Clothes | .58*** | | | | |
| Dressing | | .18 | | | |
| Room Tidy | | | .33** | | |
| Make Food | | | | .46*** | |
| Money | | | | | .32** |

** $p < .01$
*** $p < .001$

The data in Table 5B reveal that there are moderate correlations (r=.32 to .58) between self and interviewer rated behaviour in four of the independent living skills examined. In each case the relationship is highly significant. In other words, subjects' assessments of their ability to manage in the community are quite consistent with the interviewers' judgment. However, there is one exception i.e., dressing. While the subjects were very positive in assessing their ability to dress themselves, interviewers were not quite as certain that their choice of clothing was appropriate. It should also be noted that there is a moderately strong correlation between Subject Independent Living Skill Scale scores and Residential Supervisors' assessment of the subjects' level of independent living skills (i.e., r=.27, p=.01).

### 5.3.2 Residential and Work Supervisors' Rating of Subjects' Skills and Abilities

The data in Table 5C apparently indicate that Work Supervisors were more positive in their ratings of subjects' work skills and ability to function independently in a work situation, than Residential Supervisors were in assessing their independent living skills and ability. However, the figures for work skill and ability are somewhat misleading because of the relatively high frequency (22 or 24%) in the "not applicable" category. To interpret these figures it is necessary to realize that all but one subject in this category were not capable of working. If these subjects are added to those categorized as "poor" and "very poor", the difference between work and living ratings are not as great as they first appear. For both of these aspects of social integration, it seems that few of the participants in this survey were rated as highly capable of functioning independently in the community.

Table 5C

**ASSESSMENT OF SUBJECTS' SKILLS AND ABILITIES BY RESIDENTIAL AND WORK SUPERVISORS**

| | Residential Supervisor | | | | Work Supervisor | | | |
|---|---|---|---|---|---|---|---|---|
| | Skill | | Ability | | Skill | | Ability | |
| Assessment | N | % | N | % | N | % | N | % |
| Very poor | 23 | 25 | 30 | 33 | 1 | 1 | 3 | 3 |
| Poor | 25 | 28 | 30 | 33 | 8 | 9 | 17 | 19 |
| Fair | 18 | 20 | 15 | 17 | 28 | 31 | 21 | 23 |
| Good | 13 | 14 | 5 | 5 | 18 | 20 | 19 | 21 |
| Very Good | 4 | 4 | 3 | 3 | 13 | 14 | 8 | 9 |
| No response | 3 | 3 | 3 | 3 | 1 | 1 | 1 | 1 |
| Not applicable | 5 | 5 | 5 | 5 | 22 | 24 | 22 | 24 |
| Total | 91 | 100 | 91 | 100 | 91 | 100 | 91 | 100 |

In addition, it should be noted that there were limited differences in the skill and ability ratings provided by Residential and Work Supervisors. These differences were attributed by the Supervisors to the failure of a number of members of the sample to demonstrate their skills appropriately because of an inability to function well in group situations or because of personal behavioural problems.

### 5.3.3 Residential Supervisor and Interviewer Rated Socio-emotional Behavioural Problems

Both Residential Supervisors and the interviewers were asked to indicate the frequency with which each subject demonstrates a range of socio-emotional behaviours. A total of eleven different behavioural dimensions were investigated. For example, Residential Supervisors were asked: How frequently does he/she demonstrate anti-social behaviour to others? How frequently does he/she demonstrate rebellious behaviour

toward authority? How frequently does he/she demonstrate destructive behaviour toward property? How frequently does he/she demonstrate apathetic (unresponsive) behaviour? The response categories included: never (1); rarely (2); occasionally (3); and frequently (4). Scores on these eleven items were summed to form the Residential Supervisor Behaviour Rating Scale (**CRSBEHAVE**). The mean score on this scale was 22.35 (standard deviation = 6.4). Reliability analysis revealed that these eleven items form an additive scale. Corrected item-total correlation coefficients range between approximately .40 and .60 and the standardized item alpha = .81.

Interviewers were asked to indicate the frequency with which each subject demonstrates the same eleven behavioural dimensions. The items and the response categories were the same as those used for the Residential Supervisor and the identical procedure was used to construct the Interviewer Behaviour Rating Scale (**CIBEHAVE**). The mean score on this scale was 21.45 (standard deviation = 6.2). Reliability analysis once again revealed that these eleven behavioural items also form an additive scale for interviewer ratings. Corrected item-total correlation coefficients range between approximately .35 and .65 and the standardized item alpha = .82.

There is a moderately strong (r=.41) and highly significant (p=.0001) relationship between these two scales (i.e., **CRSBEHAVE-CIBEHAVE**). In other words, Residential Supervisors and interviewers' ratings of the subjects' behaviour were quite consistent. Interviewers' ratings were based, in part, on direct observational data and time spent

with each subject, but were also apparently influenced by the judgments expressed by Residential Supervisors. Relationships between the scores on these two scales and measures of community integration will be explored in a subsequent chapter.

### 5.3.4 Interviewer Rated Knowledge and Awareness Levels and Community Integration

Finally, interviewers were asked to rate the subjects' awareness and knowledge of a variety of factors on a four point scale (ranging from poor to good). For example, subjects were rated on their awareness and use of public transportation, money and budgeting. In addition, they were rated on their knowledge of shopping, meal preparation, housekeeping, personal hygiene, reading and writing. In total, subjects were rated on nineteen different factors. These factors did not form a reliable additive scale. Although alpha levels were quite high, the corrected item-total correlation coefficients in some cases were very low.

Consequently, this pool of nineteen items was subjected to a varimax rotation factor analysis. Several runs were necessary and a number of items had to be dropped before clear factors could be identified. Four subscales emerged from this analysis.

IRSPEND: This subscale consists of four items: awareness and use of public transportation, money, budgeting and shopping. Factor loadings are quite high and range from .65 to .91. This factor explains 70% of the variance and has an eigenvalue of 2.77. Furthermore, these four items form a reliable additive scale (alpha = .85). This subscale essentially measures aspects of money management.

IRTALK: This subscale consists of five items: awareness of seeking information, appropriateness of speech, appropriateness of topic of conversation, knowledge of reading and knowledge of how to follow instructions. Factor loadings range from .56 to .89. This factor explains 63% of the variance and has an eigenvalue of 3.13. These five items form a reliable additive scale (alpha = .84) which essentially measures information processing and conversational skills.

IRHOUSE: This subscale consists of three items: knowledge of meal preparation, and knowledge of housekeeping (kitchen duties and laundry). Factor loadings range from .72 to .87. This factor explains 66% of the variance and has an eigenvalue of 1.99. These three items form a reliable additive scale (alpha = .75) which essentially measures housekeeping skills.

IRPERSON: The final subscale consists of two items: knowledge of dress and personal hygiene. Factor loadings for both items are .87. This factor explains 76% of the variance and has an eigenvalue of 1.52. Although the alpha level is somewhat lower for this last subscale, these two items form a reliable additive scale (alpha = .68) which essentially measures personal care.

Correlation coefficients between these four subscales range from .19 to .45. In some cases, the relationship is moderately strong (r=.40) and significant (p=.02) e.g., IRSPEND-IRTALK, IRSPEND-IRHOUSE; while in other cases the relationship is rather weak (r=.19) and not statistically significant (p=.08) e.g., IRHOUSE-IRPERSON. Overall, these subscales are not highly inter-correlated and will be treated as independent potential

predictors of community integration in the subsequent multivariate analysis.

At the end of the data collection process, the interviewers were required to rate the ability of the subjects to live independently in the community and their overall degree of integration in the community. These ratings were on a 5 point scale, ranging from very poor (1) to very good (5). Integration was assessed on the basis of the extent of the contact subjects had with various people and services in their community. The findings are summarized in Table 5D.

**Table 5D**

**INTERVIEWER RATED ABILITY TO LIVE INDEPENDENTLY AND COMMUNITY INTEGRATION**

| | Ability to Live Independently | | Community Integration | |
|---|---|---|---|---|
| Rating | N | % | N | % |
| Very poor | 37 | 41 | 5 | 6 |
| Poor | 21 | 23 | 10 | 11 |
| Fair | 23 | 25 | 27 | 30 |
| Good | 6 | 7 | 32 | 35 |
| Very good | 3 | 3 | 13 | 14 |
| No opportunity | 1 | 1 | 4 | 4 |
| Total | 91 | 100 | 91 | 100 |

The difference in the interviewers' response to the questions is obvious from the mean scores on these two items i.e., community integration = 3.4, and ability to live independently = 2.1. In general, the interviewers' ratings for community integration, based on contact with people and services, indicate that the subjects are fairly well integrated. For example, a total of 45 (49%) subjects were rated as

"good" or better, and only 15 (17%) were rated as "poor" or worse. In contrast, the ratings for ability to live independently in the community are far less optimistic. Only 9 (10%) of the subjects were rated "good" or better, while 58 (64%) were rated as "poor" or worse. This suggests that former residents of the MDC may have been successful at becoming integrated into supervised residences and sheltered work settings, but may lack the independent living skills to function adequately on their own in the larger community.

## 5.4 SUMMARY

The way in which the Residential Supervisors and interviewers rated the subjects' ability to live independently in the community indicates that, except for a very small number, this group of individuals were not considered capable of functioning on their own in the community. For example, two-thirds of the subjects received a rating of "poor" or "very poor" (i.e., Residential Supervisors = 66%; interviewers = 64%). In other words, most of the participants in the study were judged to be lacking necessary independent living skills. In fact, only 8-10% were rated as "good" or better on this dimension. It is only within the confines of a sheltered workshop that the subjects were more likely to be positively rated (i.e., Work Supervisors rated 30% of the subjects as "good" or "very good" in terms of their ability to function independently in a work situation).

It is interesting to note that Residential Supervisor (CRSBEHAVE) and Interviewer (CIBEHAVE) Behaviour Rating Scale scores were not

significantly related to their overall assessment of the subjects' ability to live independently in the community (i.e., Residential Supervisor - $r = .07$, $p = .26$; interviewer - $r = -.06$, $p = .30$). It seems that the lack of independent living skills, and not the presence of socio-emotional behavioural problems, is the critical factor in this assessment of the subjects' potential for community integration.

# CHAPTER 6 - PUBLIC ATTITUDES TOWARD THE MENTALLY RETARDED IN THE COMMUNITY

## 6.1 THE NEIGHBOURHOOD ATTITUDE SURVEY

In designing this study, it was anticipated that life in the community for the discharged mentally retarded would be affected by a variety of factors. It was assumed that personal factors (e.g., socio-demographic characteristics, institutional experience); residential factors (e.g., size and location of residence); and community factors (e.g., neighbours' attitudes) would all influence the social integration of the mentally retarded persons in the Community Sample. To measure public receptivity to community living arrangements for former MDC residents, a neighbourhood attitude survey was conducted.

For each of the ninety-one subjects in the Community Sample, four people living in the immediate area were randomly selected and asked to participate in the survey. A total of 364 adult neighbours were approached and 243 agreed to be interviewed. This represents a 67% response rate. The data in Table 6A indicate that the distribution of neighbourhood respondents by Health Region closely resembles the provincial distribution of subjects in the Community Sample. For example, 33% of the subjects and neighbours interviewed live in Winnipeg.

Table 6A

DISTRIBUTION OF COMMUNITY SAMPLE AND NEIGHBOURS BY HEALTH REGION

| | Subjects | | Neighbours | |
|---|---|---|---|---|
| Health Region | N | % | N | % |
| Winnipeg | 30 | 33 | 80 | 33 |
| Central | 23 | 25 | 66 | 27 |
| Interlake | 6 | 7 | 13 | 5 |
| Westman | 9 | 10 | 20 | 8 |
| Eastman | 11 | 12 | 33 | 14 |
| Parkland | 12 | 13 | 31 | 13 |
| Total | 91 | 100 | 243 | 100 |

The objectives of the Neighbourhood Attitude Survey were: to gain some basic socio-demographic information about the neighbours of the Community Sample; to find out if the neighbours know that there are mentally retarded people living in community residences in the immediate neighbourhood; and to determine how close a relationship neighbours find acceptable with mentally retarded people in the community. To measure public attitudes, each neighbour was asked to respond (strongly agree-strongly disagree on a five point scale) to 10 Likert-type items adapted from a standardized social acceptance/distance scale. Casewise mean substitution was used to minimize the problem of missing data. Responses were then subjected to a varimax rotation factor analysis and two components were extracted. These two subscales measure public acceptance of mentally retarded persons into: (1) distant/secondary relationships (MDISTANT); and (2) close/primary relationships (MCLOSE).

The first subscale (MDISTANT) consists of five items: "I would be willing to work on the same job with a mentally retarded person"; "I

would be willing to sponsor a mentally retarded person for membership to my favourite club or group"; "If I was a manager and responsible for hiring people at work, I would be willing to hire a mentally retarded person"; "If I was responsible for renting apartments in a building, I would not hesitate to rent living quarters to a mentally retarded person"; and "I would marry a member of a family in which there is mental retardation". Factor loadings for these five attitudinal items range from .63 to .77. This factor explains 38% of the variance and has an eigenvalue of 3.02. Furthermore, these five items form a reliable additive scale (alpha = .78).

The second subscale (MCLOSE) consists of three items: "I would never trust anyone who is mentally retarded to look after my children, even for a short period of time"; "I would discourage my children from dating or marrying anyone who is mentally retarded"; and "I would not lend money to a person who is mentally retarded". Factor loadings for these three attitudinal items range from .50 to .79. This second factor is not quite as strong and explains only 14% of the variance (and has eigenvalue of 1.12). These items do not form quite as reliable a scale (alpha = .47).

It should be noted that correlational analysis revealed that scores on these two attitude subscales are not related (r=.0002, p=.49). In other words, acceptance of mentally retarded persons in the community into one type of social relationship is not necessarily associated with acceptance in other social situations.

## 6.2 CHARACTERISTICS OF THE NEIGHBOURHOOD RESPONDENTS

All of the neighbours who were interviewed were asked to provide basic socio-demographic information (i.e., sex, age, education and occupation). The socio-demographic characteristics of neighbourhood respondents are summarized in Table 6B.

Table 6B

DISTRIBUTION OF NEIGHBOURHOOD RESPONDENTS BY SOCIO-DEMOGRAPHIC CHARACTERISTICS

| | Sex | |
|---|---|---|
| | N | % |
| Male | 80 | 33 |
| Female | 163 | 67 |
| Total | 243 | 100 |

| | Age | |
|---|---|---|
| | N | % |
| Under 20 | 3 | 1 |
| 20 - 29 | 38 | 16 |
| 30 - 39 | 45 | 19 |
| 40 - 49 | 37 | 16 |
| 50 - 59 | 35 | 15 |
| 60 - 69 | 45 | 19 |
| 70 - 79 | 27 | 12 |
| Over 80 | 5 | 2 |
| Total | 235 | 100 |

Table 6B Continued

| | Education | |
|---|---|---|
| | N | % |
| Grade 9 or less | 78 | 32 |
| Some high school | 60 | 25 |
| Completed high school | 48 | 20 |
| Other post-secondary | 25 | 10 |
| Some university | 31 | 13 |
| Total | 242 | 100 |

| | Employment Status | |
|---|---|---|
| | N | % |
| Employed | 135 | 56 |
| Keeping house | 81 | 33 |
| Unemployed | 27 | 11 |
| Total | 243 | 100 |

Two-thirds of the neighbours who participated in this survey are female (i.e., women are overrepresented). Age and education of neighbourhood respondents varied widely. Respondents ranged in age from 18 to 86. Respondents were quite evenly distributed across age categories and the mean age was 48 years (standard deviation = 17.3). While approximately one-third of the respondents had only completed a maximum of nine years of formal education, on average most respondents had attended/completed high school. In addition, 23% had received some form of post-secondary or university education. Finally, 56% of the respondents reported that they are gainfully employed. Respondents are employed at a wide range of occupations and the most frequently cited include: farmer, teacher, clerk/cashier and salesperson. One-third of

the respondents described themselves as keeping house, and the remainder were unemployed (including those who were students and retired).

In summary, then, the typical respondent in the Neighbourhood Attitude Survey was a 48 year old woman with a high school education, who was either keeping house or working outside the home at a clerical or service occupation.

## 6.3 PUBLIC ATTITUDES: SOCIAL ACCEPTANCE OF MENTALLY RETARDED PEOPLE IN THE COMMUNITY

The attitude subscale scores indicate that participants in the neighbourhood survey find distant/secondary relationships with mentally retarded people somewhat more socially acceptable than close/primary relationships. However, the overall attitudes of Manitoba residents toward mentally retarded persons in the community are quite positive (i.e., there were no systematic differences in public attitudes by Health Region). For example, approximately three-quarters of the respondents (76-78%) find working relationships with mentally retarded persons acceptable (i.e., they agreed/strongly agreed to work on the same job, hire a mentally retarded person). A slightly lower proportion (68%) expressed favourable attitudes toward renting living quarters to a mentally retarded person and marrying into a family in which there is mental retardation. The lowest level of agreement with items on the MDISTANT Scale centered on the respondents' willingness to sponsor a mentally retarded person for membership in a club/group. While only 62% agreed with this attitudinal item, it should be noted that most of the

other respondents (25%) were simply undecided rather than negative in their attitudes.

Turning to the second attitude subscale (MCLOSE), the findings are not quite as positive. Fifty-six percent of the respondents would not discourage their children from dating or marrying someone who is mentally retarded, and only 42% would trust someone who is mentally retarded to look after their children. Once again it is important to recognize that a small proportion of the respondents (20%) actually expressed negative attitudes regarding these items. In fact, many members of the general community are simply undecided (i.e., 35% of the respondents stated that they were not certain whether they would allow a mentally retarded person to look after their children).

The most negative attitudes expressed were toward lending money to a mentally retarded person (i.e., only 31% were willing). Almost half the respondents interviewed (48%) would not lend money to a person who is mentally retarded. It is quite intriguing to learn that twice as many respondents would object to loaning money, than to having one of their children date or marry someone who is mentally retarded. Perhaps this reveals more about their attitude toward money than toward the mentally retarded. It would be interesting to know how these respondents feel about lending money to other members of the community.

Do scores on these two attitude subscales vary in terms of the socio-demographic characteristics of respondents? To answer this question, the strength and significance of the association between attitude scores (MDISTANT, MCCLOSE) and the respondents' sex, age,

education and employment status were examined. Sex was not significantly related to either attitude measure. This is an important finding in view of the overrepresentation of women in this survey. In other words, the essentially positive public attitudes identified in this study are not directly related to the fact that most of the respondents (67%) are female. Employment status was also not significantly related to these two attitude measures.

In contrast, respondents' age and level of education were found to be significant correlates of neighbours' attitudes toward accepting mentally retarded persons in both distant/secondary and close/primary social relationships. There is a statistically significant, inverse relationship between age and MDISTANT ($r=-.25$, $p=.0001$) and MCLOSE scores ($r=-.19$, $p=.001$). In other words, younger respondents have more positive attitudes. Finally, education is directly related to public attitudes toward mentally retarded persons (MDISTANT, $r=.34$, $p=.0001$; and MCLOSE, $r=.18$, $p=.003$). In summary then,, younger respondents and those with higher levels of formal education expressed the most positive attitudes toward mentally retarded people living in the community.

## 6.4 KNOWLEDGE OF MENTALLY RETARDED PEOPLE LIVING IN THE NEIGHBOURHOOD AND VIEWS ABOUT COMMUNITY RESIDENCES

The Neighbourhood Attitude Survey contained two additional general questions: (1) Do you know if there are any people who are mentally retarded living in your (immediate) neighbourhood? and (2) How do you feel about the existence of community residences for people with mental retardation? Sixty-percent of the respondents know that there are

mentally retarded people living in their neighbourhoods. In contrast, 37% of the respondents stated that there are no mentally retarded people living in their immediate neighbourhood! Due to the sampling strategy used, all participants in the neighbourhood survey have some type of community living arrangement for mentally retarded persons in their area. Apparently over one-third of the community residents are not aware of this fact.

The vast majority of the respondents interviewed (81%) either favour or strongly favour the existence of community residences for people with mental retardation. Fourteen percent are uncertain and only 5% oppose community residences. In concluding the analysis of the neighbourhood data, the relationships between these two general questions and the attitude measures (MDISTANT and MCLOSE) were explored. As might have been anticipated, public views about community residences and attitudes toward mentally retarded persons are inter-related (i.e., MDISTANT, r=.35, p=.0001; and MCLOSE, r=.29, p=.0001). Those neighbours who favour the existence of community residences for people with mental retardation are more willing to accept various types of social relationships with the mentally retarded.

Do the attitudes of respondents who know that there are mentally retarded people living in their immediate neighbourhood differ from those who do not know that this is the case? Correlational analysis revealed that there is a weak but significant association between knowledge level and public attitude (i.e., MDISTANT, r=.12, p=.04; MCLOSE, r=.18, p=.003). These findings suggest that neighbours who know there are

mentally retarded people living close to them have more positive attitudes.

To explore this relationship further, respondents were categorized into two groups: (1) Group One - those who know there are mentally retarded people living in their neighbourhood (n=147); and (2) Group Two - those who do not know that there are mentally retarded people living in their neighbourhood (n=89). T-tests were used to determine whether there are significant differences in the mean attitude scores (MDISTANT and MCLOSE) for these two groups of community residents.

Table 6C

RELATIONSHIP BETWEEN KNOWLEDGE OF MENTALLY RETARDED PEOPLE LIVING IN THE NEIGHBOURHOOD AND PUBLIC ATTITUDES

| | t | df | p |
|---|---|---|---|
| Acceptance in Close Relationships | -2.69 | 171.07 | .008 |
| Acceptance in Distant Relationships | -1.78 | 187.88 | .076 |

The results of the T-tests are presented in Table 6C and clearly demonstrate that there is a significant difference between these two groups on the MCLOSE Scale (p=.008) but not on the MDISTANT Scale (p=.076). In other words, this type of knowledge does not seem to be related to public attitudes toward accepting mentally retarded people in distant/secondary social relationships. However, those neighbours who know there are mentally retarded people living nearby have significantly higher mean scores on the attitude scale which measures acceptance in

close/primary social relationships. This finding has important implications for community placement of discharged mentally retarded persons and for fostering closer social contacts between mentally retarded people and other neighbourhood residents.

# CHAPTER 7 - IDENTIFYING THE PREDICTORS OF COMMUNITY INTEGRATION

For the purposes of this study, community adjustment was conceptualized in terms of: degree of social integration and perceived quality of life. Quality of life findings will be discussed in the next chapter, while the present analysis focuses exclusively upon the social integration of former MDC residents. The explicit objectives of this stage of the analysis were: (1) to identify and assess the individual and combined effects of a range of personal, residential and neighbourhood factors on community integration of the mentally retarded; and (2) to evaluate the extent to which these factors can account both for variance in the degree of social integration among the deinstitutionalized mentally retarded living in the community and for differences between the mentally retarded who have successfully re-entered the community and those who have returned to the institution. To achieve the first objective, relevant data collected from the Community Sample were subjected to a multiple regression analysis. The second objective required a matched-pairs analysis of a subgroup selected from the Community Sample and the Reinstitutionalized Sample.

## 7.1 BEHAVIOURAL INDICATORS OF SOCIAL INTEGRATION

Social integration was operationally defined in this study as including: community productive participation (working); use of community resources (public transportation); and size and composition of social networks (i.e., friends and neighbours). Five specific measures of

community integration were used for the multivariate analysis:

(1) CWORKING - subject presently working (yes/no);

(2) KINTRAN2 - kind (usual mode) of transportation used by subject. Responses were categorized as - public (e.g., city bus, or taxi) and provided (e.g., organization owned van or handi-bus);

(3) NBRNAMES - knowledge by subject of the names of people who live nearby (i.e., whether or not subject knows the names of immediate neighbours);

(4) NFRIENDS - feeling by subject that he/she has - a lot of friends, a few friends, or no friends;

(5) NMRPALS - number of friends subject has who are not mentally retarded.

Continuous measures such as NFRIENDS and NMRPALS were not recoded, however, categorical measures such as CWORKING, KINTRAN2 and NBRNAMES were recoded as dummy variables. Higher scores were always interpreted as evidence of better social integration (i.e., CWORKING - yes [1], no [0]; KINTRAN2 - public [1], provided [0]; and NBRNAMES - yes [1], no [0]. The five measures were treated as separate indicators of social integration and these dependent variables were not collapsed or combined in the present analysis as a composite measure of overall degree of integration. This decision was based on empirical evidence indicating that there are weak and essentially nonsignificant relationships among these aspects of community integration.

## 7.2 PREDICTORS OF SOCIAL INTEGRATION

A range of potential predictors of social integration were investigated in this study. These predictors may be categorized as personal, residential and community factors. Personal factors were dividided into socio-demographic and behavioural characteristics of the individual and institutional experience. In summary, the independent variables used in the multivariate analysis include:

(1) Personal Factors

(a) Socio-demographics, independent living skills, and behavioural ratings (n=10)

YRBIRTH1 - age in years,

SEX - male/female

IQ - full scale WAIS

ILSCALE - Subject Independent Living Skills Scale

CRSBEHAV - Residential Supervisor Behaviour Rating Scale

CIBEHAVE - Interviewer Behaviour Rating Scale

IRSPEND, IRTALK, IRHOUSE, IRPERSON - four subscales scores based on interviewers' ratings of the subjects' knowledge and awareness of money management, conversational and communication skills, housekeeping skills, and personal care.

(b) Institutional experience at the Manitoba Development Centre (n=4)

YRLDCHRG - date of last discharge from the MDC

NRADMIT1 - number of times readmitted to the MDC

TYRINST - total number of years spent in the MDC

EDCTRMS - education/training received at the MDC to prepare subject for community living (yes/no)

(2) Residential Factors (n=4)

LOCRES1 - location of residence - downtown Winnipeg, suburban Winnipeg, town non-Winnipeg, rural farm

TYPERES2 - type of residence - supervised (MR worker), foster/house parent, independent living arrangement

MRMATES - size of residence - i.e., number of mentally retarded co-residents living with subject

LEVELSUP - level of supervision in the residence i.e., Residential Supervisors' rating as - limited, moderate, extensive

(3) Community Factors (n=4)

EDUCTR1 - education/training received since leaving the MDC (yes/no)

HELPER1 - availability of a community based advocate i.e., someone who helps the subject with things he/she finds difficult (yes/no)

MDISTANT, MCLOSE - two neighbour attitude subscales which measure community acceptance of mentally retarded persons into distant/secondary and close/primary social relationships

## 7.3 EXPLAINING SOCIAL INTEGRATION: RESULTS OF THE MULTIVARIATE ANALYSIS

A multiple regression analysis was performed on the data collected from the Community Sample to assess simultaneously the relationships between the various independent variables (personal, residential and

community factors) and each of the five selected measures of the dependent variable - social integration. Dummy variable recodes were used when necessary to facilitate the regression analysis. The primary purpose of this analysis was to test the combined predictive utility of these factors in explaining variation in the social integration of mentally retarded persons in Manitoba. In addition, the ultimate objective was to identify the best set of predictors of successful community integration. The analysis of these data was done in several successive stages.

First, each of the five measures of social integration (CWORKING, KINTRAN2, NBRNAMES, NFRIENDS, and NMRPALS) was run using all twenty-two of the potential predictor variables. These independent variables were grouped and entered into the regression equation as four explanatory models i.e., Personal Behavioural Factors, Personal Institutional Factors, Residential Factors and Community Factors. The intent of this stage of the analysis was to identify those independent variables which are significantly related to the measures of social integration and to test the relative explanatory power of the alternative models. For example, are personal factors more/less important than residential or community factors in explaining the social integration of the mentally retarded?

## Table 7A

**STANDARDIZED REGRESSION AND $R^2$ COEFFICIENTS FOR THE FACTORS USED IN PREDICTING SOCIAL INTEGRATION**

| Predictors | | Measures of Social Interaction | | | | |
|---|---|---|---|---|---|---|
| Personal/Behavioural | | CWORKING | KINTRAN2 | NBRNAMES | NFRIENDS | NMRPALS |
| Age | | -.19* | NS | NS | NS | -.31** |
| Sex | | -.35*** | -.31** | NS | .24* | NS |
| IQ | | NS | NS | .46*** | -.28* | NS |
| ILSCALE | | 1.43*** | .21* | NS | NS | NS |
| CRSBEHAVE | | NS | .47** | -.23* | NS | -.27* |
| IRSPEND | | -1.77*** | NS | NS | NS | NS |
| IRTALK | | .37** | NS | -.64*** | .98*** | NS |
| IRHOUSE | | .68*** | .45*** | NS | -.66*** | -.32** |
| IRPERSON | | .20* | NS | NS | NS | NS |
| | $R^2$ | (.63) | (.38) | (.11) | (.33) | (.26) |
| Personal/Institutional | | | | | | |
| Date of last discharge | | NS | NS | NS | NS | NS |
| Times readmitted | | -.25* | NS | NS | NS | NS |
| Total years | | NS | -.24* | -.23* | NS | NS |
| Education/Training | | NS | .28* | .28* | -.58*** | -.24* |
| | $R^2$ | (.03) | (.03) | (.05) | (-.01) | (.06) |
| Residential | | | | | | |
| Location of residence | | NS | .61*** | NS | NS | NS |
| Type of residence | | NS | NS | .48*** | NS | NS |
| Size of residence | | NS | NS | .46*** | NS | NS |
| Level of supervision | | NS | -.39*** | NS | NS | NS |
| | $R^2$ | (-.03) | (.48) | (.10) | (.05) | (.02) |
| Community | | | | | | |
| Education/Training | | NS | NS | NS | NS | NS |
| Available helper | | NS | NS | NS | .30** | NS |
| MDISTANT | | NS | .32** | NS | NS | NS |
| MCLOSE | | NS | NS | NS | NS | -.27* |
| | $R^2$ | (.002) | (.05) | (-.016) | (.09) | (.05) |

* $p < .05$
** $p < .01$
*** $p < .001$

The findings are summarized in Table 7A. With only two exceptions, essentially all of the independent variables were found to be significantly related to at least one of the measures of social integration. Date of last discharge from the MDC and education/training received in the community were not related to any of the dimensions of integration included in this study. This finding may be explained in part by the fact that very few of the respondents (23%) had actually received any education or training programs since being discharged from the Manitoba Development Centre.

At the same time, it is important to note that these predictors were not consistently related to all five measures of social integration. In fact, no one independent variable was significantly related to all dimensions of integration. In some cases the independent variables were significantly related to only one particular measure of integration, but not to the others. For example, IRSPEND is significantly related to CWORKING but not to the other four dimensions of social integration. In other cases, certain independent variables were related to several of the measures of social integration and seem to have a broader impact on community living for the mentally retarded. For example, variables such as IRHOUSE, IRTALK and CRSBEHAVE were significantly related to three or four aspects of integration.

Turning to the relative explanatory power of alternative models (i.e., Personal Behavioural, Personal Institutional, Residential, and Community) it was found that Personal Behavioural Factors were associated most clearly with social integration as measured in this study. For

example, the amount of variance explained by these factors was consistently higher than the variance explained by subjects' institutional experience and residential or community factors. Again there is one exception to this general pattern. That is, Residential Factors ($R^2$ = .48) explained more of the variance than Personal Behavioural Factors ($R^2$ = .38) in the kind of transportation typically used. In any case, Personal Behavioural Factors emerged as powerful predictors of most of these dimensions of social integration (e.g., CWORKING - $R^2$ = .63; NFRIENDS - $R^2$ = .33; and NMRPALS - $R^2$ = .26). In contrast, Personal Institutional, Residential and Community Factors all account for less than ten percent of the variance in most of the dimensions of social integration.

In view of the fact that the five measures of integration used in this study are not closely inter-related, it is not surprising to find that there are differences in the specific predictors significantly associated with each dimension of community integration. For example, interviewer rated money management and housekeeping skills, along with subject rated independent living skills and sex (i.e., male) were the factors most closely associated with employment status (CWORKING). Location of residence and level of supervision are the best predictors of the kind of transportation used (KINTRAN2). In other words, respondents who live in more urban areas (as expected), and in community living arrangements with limited supervision are the ones most likely to use public transportation on a regular basis. In addition, personal behavioural factors such as interviewer rated housekeeping skills,

residential supervisor behaviour ratings and respondents' sex (i.e., male) were also significantly related to the use of public (rather than provided) transportation.

Very few of the independent variables investigated proved to be good predictors of the other three dimensions of social integration. Knowledge of the names of immediate neighbours (NBRNAMES) was most closely associated with type and size of residence, subjects' IQ score and interviewer rated conversational/communication skills. In other words, those subjects who reside in larger and more independent community living arrangements are most likely to know their neighbours by name. Respondents self-assessed friendship network (NFRIENDS) was most closely associated with interviewer rated housekeeping and communication skills, along with education/training received in the MDC. Finally, the number of non-mentally retarded friends reported by each subject was most clearly related to interviewer rated housekeeping skills and the respondents' age. Older subjects apparently are less likely to have friends in the community who are not mentally retarded persons.

The next step in the multivariate analysis was to take only those independent variables found to be significantly related to each of the measures of social integration in the first stage and enter them into a stepwise multiple regression. In addition to excluding nonsignificant factors, a couple of other independent variables (e.g., IRSPEND) were deleted to minimize problems of multicollinearity. This time, the remaining predictors were not grouped by category (e.g., Residential Factors) but were all allowed to "compete" with one another to try to

identify the best set of predictors of social integration, while controlling for all other factors in the regression equation. In other words, of all of the potential predictors measured, which ones are the best at explaining variance in the five dimensions of social integration under investigation.

Table 7B

**STANDARDIZED REGRESSION AND STEPWISE $R^2$ COEFFICIENTS FOR THE PREDICTORS OF SOCIAL INTEGRATION ***

| | Measures of Social Integration | | | |
|---|---|---|---|---|
| Predictors | CWORKING | | | |
| | Beta | p | $R^2$ | $R^2$ Change |
| Number of times readmitted | -.29 | .005 | .05 | --- |
| ILSCALE | .25 | .013 | .11 | .06 |
| | KINTRAN2 | | | |
| Location of residence | .49 | .00001 | .34 | --- |
| Level of supervision | -.36 | .00001 | .48 | .14 |
| CRSBEHAVE | .37 | .00001 | .53 | .05 |
| ILSCALE | .19 | .005 | .57 | .04 |
| MDISTANT | .15 | .027 | .59 | .02 |
| | NBRNAMES | | | |
| Total years in institution | -.25 | .014 | .04 | --- |
| CRSBEHAVE | -.22 | .032 | .08 | .04 |
| | NFRIENDS | | | |
| Available helper | .38 | .0002 | .07 | --- |
| IRHOUSE | -.35 | .0004 | .17 | .10 |
| MCLOSE | -.22 | .019 | .21 | .04 |
| | NMRPALS | | | |
| CRSBEHAVE | -.31 | .002 | .06 | --- |
| IRHOUSE | -.26 | .009 | .11 | .05 |
| Age | -.23 | .02 | .16 | .05 |

* No other variables met the minimum significance level for entry into the regression equations.

The stepwise multiple regression findings are summarized in Table 7B. This stage of the multivariate analysis also highlights the importance of selected Personal (Behavioural and Institutional) Factors as the best predictors of several of the measures of integration (i.e., CWORKING, NBRNAMES, and NMRPALS). In other words, personal factors are important predictors of whether subjects are working, know their neighbours and interact with other non-mentally retarded people in the community. Once again, Residential Factors are the best predictors of the kind of transportation used by mentally retarded persons in the community. Location of residence and level of supervision explain 48% of the variance in this dimension of social integration. There was only one case (NFRIENDS), in which a Community Factor was identified as the best predictor. It is not surprising that having someone available in the community who helps with things the subjects finds difficult is closely associated with the number of self-reported friends. While the stepwise multiple regression technique is useful in isolating the best predictors of these measures of integration, it is important to note that (with the exception of KINTRAN2), a good deal of the variance in the community integration of mentally retarded persons remains unexplained.

At this stage of the data analysis, the research focus was altered somewhat. The balance of this section is devoted to examining whether the predictors of social integration identified in the analysis of the data collected from the Community Sample, are also effective at distinguishing between those mentally retarded persons who have been able to remain in the community and those who have returned to the Manitoba

Development Centre. This last phase of the statistical analysis involves a comparison of the Community Sample and the Reinstitutionalized Sample described earlier.

## 7.4 DISTINGUISHING BETWEEN THE COMMUNITY SAMPLE AND THE REINSTITUTIONALIZED SAMPLE

As a further test of the predictive utility of these Personal, Residential and Community Factors, a matched-pairs analysis was done using participants in both the Community and the Reinstitutionalized Samples. The underlying assumption was that if the factors identified by the regression analysis are indeed important to the social integration of discharged mentally retarded people living in the community, then mentally retarded persons who have returned to the institutiion from the community should differ significantly on these dimensions.

### 7.4.1 Reinstitutionalized Sample Characteristics

As described in the Research Methods Chapter, the same exclusion criteria used to define the discharged population and select the Community Sample were used for the Reinstitutionalized Sample. A comparable stratified random sample (n=30) was drawn from the mentally retarded who had returned from the community to the institution and 24 of these individuals were interviewed in the Manitoba Development Centre. The distribution of these subjects by Health Region, level of retardation, and date of last discharge is presented in Table 7C.

Table 7C

**DISTRIBUTION OF REINSTITUTIONALIZED SAMPLE BY HEALTH REGION, LEVEL OF RETARDATION AND DATE OF DISCHARGE**

| | Stratified Random Sample | | Subjects Interviewed | |
|---|---|---|---|---|
| | N | % | N | % |
| **Health Region** | | | | |
| Winnipeg | 11 | 36 | 9 | 38 |
| Central | 8 | 27 | 7 | 29 |
| Interlake | 0 | 0 | 0 | 0 |
| Westman | 4 | 13 | 3 | 12 |
| Eastman | 2 | 7 | 1 | 4 |
| Parkland | 5 | 17 | 4 | 17 |
| Total | 30 | 100 | 24 | 100 |
| **Level of Retardation** | | | | |
| Mild | 10 | 33 | 10 | 42 |
| Moderate | 10 | 33 | 10 | 42 |
| Severe | 10 | 33 | 4 | 16 |
| Total | 30 | 100* | 24 | 100 |
| **Date of Discharge** | | | | |
| 1967 - 1972 | 0 | 0 | 0 | 0 |
| 1973 - 1978 | 16 | 53 | 11 | 46 |
| 1979 - 1984 | 14 | 47 | 13 | 54 |
| Total | 30 | 100 | 24 | 100 |

* Rounded percentage

Basically the Reinstitutionalized Sample is quite representative of the population of returned mentally retarded persons in terms of Health Region and date of discharge. However, it should be noted that the

proportion of severely retarded in the sample of subjects interviewed is underrepresented due to problems encountered in collecting the required data for this subgroup.

A comparison of the characteristics of the two samples reveals some interesting differences. For example, the data in Tables 3A and 7C indicate that the proportion of mentally retarded who returned to the MDC from Winnipeg is somewhat overrepresented, and the proportion from Interlake and Eastman Regions is underrepresented. In fact, while seven percent of the Community Sample resided in the Interlake, there were no subjects in the Reinstitutionalized Sample from this region. The interpretation of this finding obviously requires additional information about the specific communities involved and the nature of the services provided for the mentally retarded in each of these Health Regions.

Turning to level of retardation, the moderately retarded are under-represented and the severely retarded are over-represented in the Reinstitutionalized Sample. This finding suggests a relationship between level of retardation and successful community placement although the regression analysis did not identify IQ as a significant predictor of social integration. Again this is a point which may warrant further study.

Finally, the proportion of mentally retarded persons discharged to the community between 1967-1972 is dramatically underrepresented in the Reinstitutionalized Sample. Twenty-one percent of the Community Sample had been discharged during this time period and yet not one person included in the sample who had returned to the MDC had been discharged

prior to 1972. This finding may be related to the length of time these people have been back in the community and the level of retardation of those discharged during this early time period. In contrast, those most recently returned to the community (1979-1984) were the ones who were overrepresented in the Reinstitutionalized Sample. However, it is important to note that once again this descriptive evidence is not consistent with the results of the regression analysis. Date of last discharge was not found to be significantly related to any of the measures of social integration.

### 7.4.2 Matched Pairs Comparison: A Further Test of the Predictors of Social Integration

The 24 subjects in the Reinstitutionalized Sample were matched with 24 individuals selected from the Community Sample. Subjects were matched by Health Region, level of retardation, date of last discharge, and sex to hold these factors constant while carrying out the matched-pairs analysis. T-tests were then run for these two groups using the independent variables identified in the regression analysis as important predictors of social integration among the Community Sample. The intent at this point was to test for significant differences on these dimensions between those mentally retarded who have successfully re-entered the community and those who have returned to the institution. The results of the T-tests are summarized in Table 7D.

Table 7D

DIFFERENCES BETWEEN THE COMMUNITY SAMPLE AND THE REINSTITUTIONALIZED SAMPLE IN SELECTED PREDICTORS OF SOCIAL INTEGRATION

| | t | df | p |
|---|---|---|---|
| Available helper | 3.92 | 46 | .0001 |
| ILSCALE | -3.83 | 23.83 | .001 |
| Number of times readmitted | -3.54 | 40.34 | .001 |
| CRSBEHAVE | 2.31 | 40.14 | .026 |

Significant differences were found between the groups of subjects in four factors: (1) the availability of a helper in the community; (2) subject rated independent living skills; (3) the number of times readmitted to the MDC; and (4) residential supervisor behaviour ratings. No other significant differences were found between the matched-pairs in any of the other predictors of community integration investigated.

The comparison revealed that those in the Community Subsample were twice as likely to have a benefactor available in the community; and were twice as likely to have a stable community placement (i.e., the mean number of times the Community Subsample subjects were readmitted was half that of those in the Reinstitutionalized Sample). In addition, significant differences between the two groups were identified in self-rated independent living scale scores and residential supervisor rated socio-emotional behavioural problems (although not always in the anticipated direction).

## 7.5 THE BEST PREDICTORS OF SUCCESSFUL COMMUNITY INTEGRATION: SOME FINAL EVIDENCE

One last step in the data analysis was carried out to test whether the best predictors of social integration identified in this study can explain whether a person will be in the community or in the institution. For the purpose of this statistical test, the matched-pairs were combined to create a new subsample (n=48). The dependent variable used in this analysis was group membership (MPAIRS). Group one consisted of those subjects who were living in the community at the time they were interviewed, and Group two consisted of those subjects interviewed in the MDC. The objective was to evaluate the extent to which the independent variables found to be significantly related to social integration (in the earlier analysis) can predict whether the mentally retarded will remain in the community or return to the institution. The independent factors were subjected to a stepwise regression and the same four factors identified by the T-tests as significant differences between the two groups emerged once again as important predictors.

Together, number of times readmitted to the MDC ($R^2$ = .30), having an available community helper ($R^2$ = .16), independent living skills ($R^2$ = .09), and (Residential Supervisor rated) socio-emotional behavioural problems ($R^2$ = .04) explained 59% of the variance in the dependent variable (i.e., group membership). In other words, knowing only these four factors it is possible to predict with reasonable accuracy (close to sixty percent) whether the mentally retarded persons included in this study will be able to maintain their community placement or be returned to the provincial institution. These findings obviously have important policy implications.

# CHAPTER 8 - QUALITY OF LIFE OF THE MENTALLY RETARDED IN THE COMMUNITY

## 8.1 DEFINING QUALITY OF LIFE

This chapter focuses upon the quality of life experienced by former MDC residents now living in the community. The issue of quality of life has become a major topic of interest to researchers working in the field of developmental delay. However, identifying what constitutes quality of life has not been an easy task and an acceptable definition remains elusive. One approach to defining quality of life has been to use descriptors based on the Principle of Normalization (Wolfensberger, 1972). However, there are serious problems associated with attempts to evaluate quality of life based upon the Principle of Normalization. The Principle has been interpreted as meaning that the environment for the mentally handicapped should be as close as possible to that of the normal population and this in turn has been interpreted as demanding the mentally handicapped live, work and play in integrated environments. Unfortunately this interpretation appears to have been widely accepted without due regard for the specialized needs of individuals within that population, for whom the integrated setting may not be the least restrictive environment.

The quality of life of the mentally handicapped is now frequently assessed, only in terms of how their living conditions measure up to the dictates of integrated environments, despite the fact that the assumptions regarding the value of integrated environments have not been adequately evaluated. Although the Principle of Normalization has been instrumental in improving living conditions for a great many handicapped

people, its application to the evaluation of quality of life represents a tautological argument that leaves unanswered the basis upon which quality of life should be assessed.

A more useful approach may be to define quality of life in terms of the physical, psychological and social needs of individuals as identified by Maslow's (1968) theory of the Hierarchy of Needs. In this theory, he describes physiological needs, psychological and physical security needs, and belonging or affiliation needs, as basic determinants of human behaviour and motivation. If these hierarchical factors, represent the basic deficiency needs of individuals, they also provide an appropriate framework for the definition of quality of life. It is, therefore, argued that these factors may be applied to the living conditions of the mentally handicapped to evaluate their quality of life.

One of the problems facing those working with the developmentally delayed is the dilemma of judging to what extent a developmentally delayed individual should have freedom of choice. The dilemma occurs because complete freedom of choice for those who have not learned adequate safety precautions or self-control could result in those individuals choosing actions that put themselves or others in jeopardy. As a consequence there are many who recommend strict control over those identified as developmentally delayed for their own protection, while others argue that such control only results in ensuring that the individuals in this situation are never given the opportunity to learn and develop control over their own behaviour. A second dilemma focuses on the degree to which goods and services should be available for those

who are unable to demonstrate the capacity for independent functioning in society.

It is within this framework that, for the purposes of this study, quality of life was defined as:

> The discrepancy between what the individual has and what the individual wants in relation to a hierarchy of basic physical, psychological and social needs with the qualification that what the individual wants should be consistent with, and appropriate for their current ability to function as an independent agent.

The interpretation of this definition is therefore that environments for the mentally retarded must provide physical, psychological and social conditions of acceptable community standards, consistent with the needs of individuals and their varying levels of interests and abilities

## 8.2 MEASURING QUALITY OF LIFE

Basic physical needs include environmental factors such as the physical adequacy of the residence and the community, health factors, access to community facilities and opportunities provided by the community for participation in various activities. Descriptive data and interviewer field notes on the physical environment suggested that basic services were satisfactory and that in most cases adequate access was available to a range of community options. Despite the availability of community facilities, the data suggest that the subjects in this study did not avail themselves of the opportunities to use these facilities, in any regular or systematic way. Although the urban environment provided the most opportunities for use of community facilities there did not appear to be any systematic use of these facilities, other than

commercial services such as provided by shopping malls and coffee shops.

Psychological needs were identified by factors such as independence, economic security, training opportunities and the presence of a helper to assist with living in the community. The items which were interpreted as indicators of independence were related to the opportunity available to individuals to make choices about the way they wanted to live. In this respect the data indicated that a good deal of opportunity was provided to most individuals to make choices about many of their daily activities. However, there were constraints placed on some individuals with respect to one aspect of independence and that relates to freedom of movement. These restrictions were explained as having been imposed for the protection of individuals unable to care for themselves. In most cases, these individuals were either infirm or had consistently displayed behaviour that indicated they were unaware of basic safety precautions. There was also evidence that certain limitations on freedom of choice were a consequence of lack of financial resources, rather than restrictions imposed by supervisory staff. Evidence of the lack of financial resources is provided by the figure for the average wage of just $16.52 per week. This figure reflects the very low remuneration received by those working in sheltered workshops and will no doubt confirm for some people the injustice and inadequacy of this kind of program for the mentally handicapped. The proponents of sheltered employment for the mentally handicapped no doubt will defend the service on the grounds that it provides an important and meaningful activity, and is training for specific work attitudes and skills, not available

elsewhere to the mentally handicapped. It is beyond the scope of this study to debate this issue, but the evidence gathered in this study is quite clear. Most of the subjects worked in sheltered workshops, received very low remuneration, and little training, and most of them had been in the same workshops for extended periods of time. Thus, the sheltered workshop environment was far from an ideal employment setting for the mentally handicapped. However, these issues are not the only ones that need to be considered in a discussion of the contribution of sheltered workshops to quality of life, but further discussion will be deferred to a later section dealing with social relationships.

Ratings of the degree of independence subjects experienced were obtained from a variety of sources, in order to gain as complete a picture as possible. Ratings were provided by residential supervisors, interviewers and the subjects themselves. The data are reported in Table 8A. The findings indicate that there were consistently high ratings of independence by each of the three groups with the interviewers' ratings being the highest.

**Table 8A**

**A COMPARISON OF SUBJECT, RESIDENTIAL SUPERVISOR AND INTERVIEWER RATED OPPORTUNITIES FOR INDEPENDENCE**

| | Subject | | Residential Supervisor | | Interviewer | |
|---|---|---|---|---|---|---|
| Rating | N | % | N | % | N | % |
| Poor | 2 | 2 | 4 | 4 | 7 | 8 |
| Fair | 17 | 19 | 23 | 25 | 13 | 14 |
| Good | 49 | 54 | 54 | 59 | 68 | 75 |
| No response | 14 | 15 | 4 | 4 | 0 | 0 |
| Don't know | 9 | 10 | 1 | 1 | 0 | 0 |
| Not applicable | 0 | 0 | 5 | 6 | 3 | 3 |
| Total | 91 | 100 | 91 | 100 | 91 | 100 |

Interviewers were also asked to rate subjects on the degree of independence they were afforded with respect to activities associated with residential living. These data are summarized in Table 8B.

**Table 8B**

**INTERVIEWER RATED INDEPENDENT SUBJECT BEHAVIOURAL ACTIVITIES**

| | Degree of Independence | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Very Limited | | Somewhat Limited | | Not at all Limited | | Don't Know | |
| Behavioural Activities | N | % | N | % | N | % | N | % |
| Come and go from the residence | 20 | 22 | 32 | 35 | 38 | 42 | 1 | 1 |
| Decorate own room | 14 | 15 | 32 | 35 | 26 | 29 | 19 | 21 |
| Choice of clothing | 3 | 3 | 32 | 35 | 52 | 57 | 4 | 4 |
| Choice of leisure activities | 4 | 4 | 19 | 21 | 65 | 71 | 3 | 3 |
| Participate in community activities | 18 | 20 | 11 | 12 | 46 | 51 | 16 | 18 |

Independence ratings were on a 3 point scale: very limited (1); somewhat limited (2); and not at all limited (3). The means on these five behavioural dimensions range from 2.2 to 2.7, indicating a generally high level of subject independence as rated by interviewers. The lower rating for "decorate room" may be attributed to some limitations imposed by shared rooms and lack of decorative items, while the lower rating for "come and go" may be attributed to restrictions placed on a number of residents who were judged by supervisors as unable to care for their own

safety or simply not capable of travelling in the community without supervision.

## 8.3 ASPIRATIONS FOR AN IMPROVED QUALITY OF LIFE IN THE COMMUNITY

Subjects were asked a series of questions about their aspirations regarding their living arrangements, their jobs and their personal relationships. Only 22 (24%) of the respondents indicated that they felt able to live without the assistance of a supervisor. Although there were 12 (13%) subjects for whom the question was not applicable, the low affirmative response to this question may be considered somewhat surprising by those who advocate more independent living arrangements for mentally handicapped individuals. A further question asked those who wished to live without a supervisor if they thought they could manage on their own. Eighteen of the original 22 replied they could manage on their own, while 2 replied they could not, and another 2 did not know. Thus, very few subjects want to, and feel confident enough to live on their own. These data should be considered in relation to the evidence that since leaving Manitoba Development Centre only 21 (23%) subjects reported they had received any kind of training. This factor, more than any other, indicates that the subjects in this study had left a large institutional setting, only to be located in other structured environments which made no better effort to train them for integration into the community. When the limited social and independent living skills of the developmentally delayed are considered, it is apparent that the lack of systematic training is one of the major problems associated

with the quality of life of those living in community residences.

As identified earlier in this report, the presence or absence of a "helper" in the community is a major determinant of successful community integration. The role of the helper is to assist the subject with tasks that he/she finds difficult and to be an advisor and benefactor. Many of the tasks undertaken by these helpers clearly involve training the subjects in areas necessary for independent living in the community. When subjects were asked, 72 (79%) reported they had helpers. But who are these community helpers? On further questioning, it was determined that 54 of the helpers are paid staff in the residences or agency workers. Only 16 reported having helpers who are family of friends. These data suggest that the important contribution to community adjustment played by the presence of a helper depends, in this population, on the presence and dedication of paid professional members of the social welfare system.

Subjects were next asked if they would like a better job and 40 (44%) replied they would, but in a follow-up question only 17 (19%) indicated that they could do the job without further training. Twelve of the respondents indicated they would need further training. When asked to elaborate on the kind of new job they would like, it was apparent that the subjects had little knowledge of the job opportunities available. One woman replied that she would like to leave the workshop to work as a baby-sitter, while a number indicated they would like to work in a kitchen or wait on tables in a restaurant. Given the low ability ratings of those who indicated they wished for better jobs, it is apparent that

the subjects lacked both the knowledge and skill to obtain better employment under existing arrangements of work and social skill training.

Subjects were also asked if there are any things they would like to do in their spare time, that they do not get to do. The 29 individuals who responded in the affirmative gave examples ranging from getting a job to being alone at home. They also expressed the desire to go out for recreation and entertainment. When asked why they did not get to do these things now, a number of respondents replied that there was no-one to take them. Another factor was the lack of finances for some of the more expensive entertainments identified. Although these responses represent a clear expression of dissatisfaction by the subjects, it must be noted that only 32% expressed these feelings. Quite clearly the wish-list for many was unrealistic, while for others the wishes could well be interpreted as expressions of loneliness.

In a final probe of their aspirations, the subjects were asked if they would like to marry. Twenty-nine percent replied "yes" and 42% replied "no". A further question asked if they would like to have a child, to which 22 (24%) replied "yes" and 42 (46%) replied "no". The relatively small number of affirmative responses to these questions may indicate a lack of concern with these topics, but may also be influenced by the relatively older age (42) of this sample of intellectually handicapped people.

## 8.4 LEVEL OF SATISFACTION WITH LIFE IN THE COMMUNITY

A major feature of the hierarchy of needs theory is that once basic

physical and psychological security needs have been met the next factor in the hierarchy is that of satisfying the need of belonging or affiliation with a social group or community. In this study, social needs were identified by the amount and nature of community resources used and the size and nature of the subjects' social network. With respect to use of community resources, the data indicated that most individuals made little use of community resources other than for informal recreation and for some shopping for small purchases. Although financial resources clearly limited the possibility of more frequent use of community resources, the evidence was that a lack of basic money management skills also contributed to this problem.

With reference to the poor financial situation of all subjects in this study, previous discussion identified the sheltered workshops and their policy of low wages as a major cause, but it must be added that the sheltered workshops also appear to play a very positive role in the life of the workers. Despite the criticisms of various aspects of the role of the sheltered workshops, the subjects almost unanimously, reported they enjoyed their work, and although some would have liked better jobs their skill levels did not suggest this was a realistic goal. An important factor in this favourable opinion by the workers would appear to be that they found rewarding inter-personal relationships in the workshops, in contrast to the general community where few of the subjects reported social contacts.

A total of 66 subjects reported at least a few friends in the workshop. Responses to the question on friendships among the non-

handicapped population produced a vastly different result. Just 22 subjects reported that they have friends who are not mentally retarded. A total of 69 subjects reported no friends in this category, or were notable to provide a usable response. Further probing of those reporting non-handicapped friends revealed that, in most cases, these friendships were with family members or with paid staff from the residences where the subject lived. These data clearly indicate that this population had not established friendships with non-handicapped people in the community at large.

Subjects were asked to give a personal rating of their satisfaction with social relationships involving their family, friends, boy or girl friend and their community helpers. Responses to these questions are reported in Table 8C.

Table 8C

LEVEL OF SATISFACTION WITH SOCIAL CONTACTS IN THE COMMUNITY

| Level of Satisfaction | Family | | Friends | | Boy/Girl Friend | | Helper | |
|---|---|---|---|---|---|---|---|---|
| | N | % | N | % | N | % | N | % |
| Don't enjoy at all | 0 | 0 | 1 | 1 | 0 | 0 | 0 | 0 |
| Don't enjoy | 0 | 0 | 1 | 1 | 0 | 0 | 1 | 1 |
| It's okay | 4 | 4 | 7 | 8 | 7 | 8 | 11 | 12 |
| Enjoy | 16 | 18 | 23 | 25 | 12 | 13 | 22 | 24 |
| Enjoy very much | 41 | 45 | 35 | 39 | 13 | 14 | 28 | 31 |
| No response | 11 | 12 | 11 | 12 | 14 | 15 | 19 | 21 |
| Not applicable | 19 | 21 | 13 | 14 | 45 | 50 | 10 | 11 |
| Total | 91 | 100 | 91 | 100 | 91 | 100 | 91 | 100 |

The means for these ratings indicate a very high overall level of satisfaction with existing social contacts (i.e., means ranged from 4.2 to 4.6 on a five point scale). In summary, it would appear that most subjects in this study feel they are satisfied with the social relationships they have in the community.

A distinctive aspect of this study was the attention paid to the role of neighbours' attitudes in influencing the community adjustment of the subjects. To complement this aspect of the study, subjects also were asked about their relationships with their neighbours. They were first asked if they knew the names of their neighbours (47% replied "yes" and 39% replied "no"). Subjects were then asked how often they spoke with their neighbours. Two subjects replied "never" or "rarely", 4 replied "occasionally", and 33 replied "frequently" or "very frequently". The subjects were asked a final question about whether they thought they spoke often enough with their neighbours. Six replied "no" and 36 replied "yes". Apparently almost half the sample knew the names of some neighbours, spoke to them quite frequently and felt they had adequate contact with these neighbours. Despite the apparent optimistic view of this segment of the sample, the sobering fact remains that 53% of the sample have no contact with their neighbours.

As a global item, interviewers were asked to rate the overall quality of life of subjects, on the basis of their contact with them and knowledge gained from other sources. According to the interviewers, these former MDC residents are enjoying a good quality of life in the community. For example, no-one was rated as "very poor" and only one

subject was rated as "poor". In the vast majority of cases, interviewers rated the subjects' quality of life as either "good" (60%) or "very good" (20%). These data were compared to the field notes that accompanied the interviewers' reports. These notes indicate that interviewers were more than satisfied with the accommodations provided for the subjects and with their opportunities to live with minimum restrictions to their general freedom.

However, these notes also suggest that interviewers interpreted the quality of life afforded subjects in accordance with their capacity to cope with independence. For example, field notes indicate that interviewers rated the quality of life of some moderately and severely handicapped individuals as "good", when that subject was provided an adequate physical and emotional environment, even though the subject had little opportunity for contact with, or integration into the community. The notion that "quality of life" is dependent upon the degree of handicap is an interpretation derived from the definition of quality of life used in this study. The interpretation is supported by the responses of subjects to questions relating to their satisfaction with their degree of independence, and their social contacts. The only qualification to the general level of satisfaction reported by the subjects is with regard to an apparent need for more opportunities to participate in recreation and entertainment outside their residences, and a desire by some to try living without supervisors and to obtain better employment. However, even these apparent expressions of dissatisfaction must be viewed with caution. Only a few subjects expressed the desire

for more opportunity for entertainment and many of these referred to types of entertainment that were either infrequent (the circus) or expensive (hockey). The desire by some respondents to live without supervisors must be interpreted in light of the data indicating a rather low rating of many subjects on their ability to live independently. The expressed desire for better work opportunities must also be interpreted in light of responses of subjects when asked to indicate what kind of jobs they would like to do. Although the jobs identified were generally realistic, their supervisor ratings indicated that they lacked the ability to function adequately in these positions. On this basis, the subjects in this study who expressed a desire for a better job did not exhibit a combination of skills and abilities necessary to enable them to function independently. Thus, their job aspirations were unrealistic.

## 8.5 LEVEL OF RETARDATION AND LIFE IN THE COMMUNITY

Further analysis of the data was carried out to assess the relationship between severity of handicap and various aspects of community life. Many of the identified significant differences are rather predictable. The data indicate that it is primarily the mildly retarded who live without supervision and who make most use of public transport. The mildly retarded are rated as having the best work skills and as having the greatest amount of independence. The mildly retarded also have more helpers available to them, presumably because many of the moderately retarded, and virtually all of the severely retarded in this study had no need of helpers to aid with integration, because they were

not considered capable of being integrated into the community.

Among the items that did not differ by severity of handicap was type of training received. However, this may have been a function of the limited amount of training received by all subjects, either before or after discharge from the institution. Other variables in which there were no differences due to severity of handicap were independent living skills and abilities. For independent living skills and abilities the explanation of this lack of difference is that ratings were low for everyone - the severe, the moderate and the mild categories. Evidently, poor ratings on independent living skills are not reserved for the more severely handicapped groups.

## 8.6 SUMMARY

Quality of life has proved to be a difficult construct to define. One reason for the difficulty has been the lack of agreement as to what specific factors should be considered in its evaluation. However, there is general agreement, that the opinion of each individual should be taken into account in determining whether that individual is enjoying a good quality of life. In accepting the importance of the individual's own view of quality of life, the issue of the functional ability of the individual automatically becomes a determining factor. The relevance of functional ability has been an assumption throughout this study and is reflected in the operational definition of quality of life. This approach does not imply that people with more severe handicaps need less, to achieve an acceptable quality of life, but it does suggest that there

may be important differences in what is necessary for them to achieve an acceptable quality of life. It is not a matter of how much, but a question of the appropriateness of what the person has, that is crucial to the evaluation of quality of life. This issue is central to our view of the appropriate strategy for evaluating quality of life for people with mental handicap. It is also our conviction that the importance of quality of life will continue to grow, as more and more of the services are delivered in community settings. It is, therefore, important that the evaluation of these services be judged on criteria that are both appropriate and realistic for this population.

For the purposes of this study, quality of life was evaluated using a framework derived from Maslow's (1968) theory of Hierarchy of Needs. The theory in part identified basic physical needs, psychological needs and belonging or social needs as hierarchical in nature and fundamental to human behaviour and motivation. Using this framework as a model, direct and indirect evidence was gathered to evaluate the quality of life of the subjects. Based on this evidence, it was concluded that the physical needs of the subjects were adequately satisfied. Although, physical conditions were seldom extravagant they were generally appropriate and serviceable for the needs of this population.

On the question of psychological needs, several interviewers commented on the pleasant atmosphere present in many of the residences and the "family-like attitude" engendered by many of the group home supervisors. There appears to be considerable evidence of this type to demonstrate that the residents were living in a warm, supportive non-

stressful environment, which provided them with freedom of choice and independence in keeping with their abilities.

There were few who aspired to live in different circumstances and, of those who did wish to live elsewhere, most recognized they were not yet ready to live without supervision. However, the question of training to live more independently in the community and of providing the necessary psychological supports to achieve this goal was one area in which this survey identified serious weaknesses. Few individuals, either before or after leaving the MDC, had received training in skills necessary for independent living. The evidence suggests that the subjects in this study had been relocated in the community, but that deinstitutionalization had taken place without an adequate strategy to guide the process of community placement. As a result, the allocation of resources proved to be haphazard and there are serious gaps in essential services. The most crucial of these service gaps appears to be in relation to training in independent living skills which are vital to community integration. A similar criticism may be applied to the role of community "helper". As identified elsewhere in this report, the presence of a community "helper" proved to be a critical factor in the community adjustment of these subjects. In this study, the great majority of respondents reported they had a helper but 75% of these helpers turned out to be the staff in the residences or in the offices of the Department of Community Services. Although it could be legitimately argued that these professionals are in the best position to play the role of community "helper" it was also evident that because of case loads they

were not in a position to fulfill this role adequately.

Data on the affiliation or social needs among this population provide important insights into the lives of these former residents of the MDC. Although a small number reported having family with whom they visited, the great majority of the sample either had no family or saw them infrequently because they lived in other towns. Under these circumstances they relied on the companionship of those with whom they lived or worked. In addition, they relied almost exclusively on the residence for the organization of their lives outside of their work experience. Very few of the sample had any contacts outside of the residences and few made any substantial use of community resources. As indicated previously, these individuals relied almost exclusively on paid professionals to train, direct and organize them in their life activities. The evidence indicates that the subjects were given freedom of choice and were free to exercise a measure of independence but rarely used this freedom to make social contacts outside their place of work or residence. The question is why? The answer we believe is that the subjects in this study satisfied their affiliation needs with co-residents and co-workers, and they found in the residences the supportive environment that met their physical and psychological needs for security. With a group of individuals inexperienced and unskilled in living in the community and receiving only minimal training to do so, most of this group did not have the skills, or the inclination, to enter and participate in the broader social life of the community. It must be emphasized that this conclusion makes no value judgments about whether

residents should be content to live in relative segregation with their own peer groups. The facts are that is how they do live, and in terms of the definition of quality of life used in this study, their affiliation needs were being met adequately in this context.

In conclusion, it can be stated that the subjects were living in a physical, psychological and social environment that provided them with a quality of life that was reasonably adequate given their level of functional ability. The one serious qualification relates to the poor training provided to help them live more independently or to obtain better work skills. These limitations do not cause serious problems with relation to their present quality of life, but do have implications for their ability to enter into the broader life of the community and to improve the quality of their life in the future.

# CHAPTER 9 - SUMMARY AND CONCLUSIONS

## 9.1 THE STUDY DESIGN

The present study was designed primarily to investigate the community adjustment of former residents of the Manitoba Development Centre (formerly the Manitoba School for Retardates). Community adjustment was defined as comprising the degree of social integration and the quality of life of the former residents. A secondary purpose was to identify determinants of community adjustment using personal, residential, and neighbourhood factors as the independent variables.

The subjects comprised two groups of former residents of the Manitoba Development Centre discharged between 1967 and 1984. The discharged population was stratified in terms of (1) date of discharge, (2) level of retardation, and (3) Health Region in the Province of Manitoba. The two groups consisted of a Community Sample of one hundred and sixteen subjects and a Reinstitutionalized Sample of thirty subjects who had lived in the community, but had been returned and were again living in the institution. The response rate for these samples was ninety-one subjects (78%) and twenty-four (80%) respectively. Comparison of the original stratified samples and the actual respondents to the questionnaire indicated that the respondents were representative of the original samples and that no bias was present in the responding group. The investigation of the Community Sample was carried out by means of a questionnaire which was administered by a group of trained interviewers. Information was obtained from subject files and directly from subjects,

residential supervisors, community workers and where applicable work supervisors. In addition, information was obtained by interviewing two hundred and forty-three neighbours of the community living subjects. Data on the Reinstitutionalized Sample were obtained from subject files and from information supplied by the subjects and by MDC staff.

Data analysis was carried out in stages, commencing with the computation of descriptive statistics for all measures, followed by bi-variate and then multi-variate techniques. The major findings of the study have been organized in the same sequence as that of the data analysis. In addition responses to a number of open-ended questions, and information from interviewer field notes have been incorporated into the interpretation and discussion of results.

## 9.2 SUMMARY OF MAJOR FINDINGS

Descriptive data on the Community Sample indicate that there were slightly more females than males, and that the average IQ was 53 and the average age 42 years. This group had spent an average of 13 years in the MDC and approximately 25% had been re-admitted at least once. A total of 57 (63%) had some degree of physical disability and 23 (25%) were reported as displaying an identifiable stereotypic behaviour.

Analysis of the community living arrangements indicated that one-third of the sample lived in Winnipeg, while most of the others lived in towns and a few lived on farms. Most of the sample (79%) lived in community residential facilities with paid staff, while a few lived independently or with parents. Most of the residences had approximately

two supervisors and although there was considerable range in the number of residents, the average was just under four persons per residence. Within the residences, relationships between supervisors and subjects and between co-residents and subjects were reported as being good to very good. In these residences subjects were expected to assist with light household duties and most were given a good deal of freedom of choice and independence. A major restriction on choice appeared to be a consequence of lack of finances, rather than restrictions imposed by supervisors. It should be remembered, however, that these comments apply to the "average" subject and that some subjects were restricted because of a reported inability to take care of themselves and for safety and security reasons.

Recreational activities were occasionally reported as being organized within the residences, but bowling with handicapped groups was one of the few organized activities in which subjects participated at the community level. Virtually no subjects participated in organized recreational activities with the non-handicapped in the community. Similarly, few subjects relied on community transport to take them either to their work or to their recreational activities. When transport was required, it was provided especially for the handicapped group.

Most subjects reported having parents although more than half were located in different towns. Despite the distance, most reported seeing their families regularly and enjoyed visiting with them. Similarly, most subjects reported having friends, seeing them regularly and enjoying their visits. However, of the ninety-one subjects, only one reported being married and only thirty-six (40%) reported a close relationship

with someone of the opposite sex.

On the question of non-handicapped friends, the twenty-two positive replies resulted in an average of 2 persons. However, this figure is inflated by two replies that indicated fifteen and twenty non-handicapped friends. The remaining twenty replies varied between one and seven non-handicapped friends. The other sixty-nine responses were comprised of the following: no friends (20), no response (29), don't know (20), which translates into a cumulative total of 76% of the respondents who failed to report having a non-handicapped friend. Judging by the interviewers' comments, even those who did identify non-handicapped friends may have been identifying their supervisors or community workers as their friends.

A high proportion of the sample (67 or 74%) reported that they were working, but almost all (65) were working in some kind of sheltered employment. The number of hours worked averaged 34 hours, but the average wage of the group was only $16.50 per week. Almost all the workers reported they enjoyed their work, although a relatively high proportion (40 or 44%) indicated they would like a better job. However, only 17 (19%) felt they could do the job they chose without additional training, which highlights the fact that only 14 (15%) reported receiving work training since leaving the MDC. Even so, work supervisor ratings of work skill for those who were employed were quite positive. However, these ratings do not include a significant proportion (25%) who did not respond to the question and who in fact were not working. When this group is included in the analysis of work skill, the overall result is

much less favourable. The data on social relations in the work place were very positive, with most respondents reporting they had many friends among their co-workers. Work supervisors reported very good relationships between themselves and the workers indicating that the work environment provided the subjects with the opportunity for supportive and rewarding interpersonal relationships.

Data collected on the ability of subjects to perform specific independent living skills divide into personal care skills which were rated as good and skills related to housekeeping which were generally rated as poor. Ratings by residential supervisors of the independent living skills and abilities of subjects were generally very low. The ratings of their ability to live independently in the community were also extremely low, with only 10% rated as good or very good on this item.

A comparison of the self-ratings of subjects and the interviewers' ratings of subjects indicated a high correlation on all items except dressing. On this item the interviewers rated the subjects less favourably due to their inappropriate choice of clothing. On the eleven items forming the behaviour rating scale, a very high positive correlation was found between residential supervisor ratings, and interviewer ratings. These behaviour ratings were significantly related to a number of measures of community integration and in the comparison of the Community and Reinstitutionalized Samples was a significant predictor of community integration.

A unique feature of this study was the inclusion of a neighbourhood attitude survey. This survey was included on the basis of evidence that

successful community adjustment depends, in part, on the attitude of the community toward the mentally handicapped. Using an instrument adapted from a standardized community acceptance/distance scale a total of 243 neighbours of the subjects were interviewed. The data provided by these neighbours were analyzed and the results indicated that overall attitudes to the mentally retarded were quite positive, although distant/secondary relationships with mentally handicapped people were more socially acceptable than close/primary relationships. The relationship between attitudes towards the mentally handicapped and certain characteristics of the respondents was explored and revealed that there was no difference due to sex or employment status. On the other hand, younger respondents and those with higher levels of formal education expressed significantly more positive attitudes. In a response of some significance for social services planning, 81% of all respondents indicated they were in favour or strongly in favour of community residences for the mentally handicapped.

At the next stage of data analysis a multiple regression analysis was used to assess the individual, and combined effects, of personal, residential and neighbourhood factors on the community integration of the subjects. A range of potential predictors of social integration was investigated and it was found that personal behavioural factors were most clearly associated with social integration as measured in this study. The next procedure was to identify all those items found significantly related to each of the measures of social integration and enter them into a stepwise multiple regression. Once again, personal factors are the

best predictors of several of the measures of integration.

A further test of the predictive utility of the personal, residential and neighbourhood factors was performed on a matched-pairs sample of community and reinstitutionalized subjects. Using the independent variables identified in the regression analysis as predictors of social integration, a series of t-tests were run on the means of the two groups. Significant differences were found between the groups on four factors:

1. The availability of a helper;
2. Subject rated independent living skills;
3. The number of times re-admitted to the MDC;
4. Residential supervisor rated behaviour.

The final step in this analysis was to test the predictive validity of the items identified in the previous stages of the analysis. Using the same subgroup of subjects, the independent factors were subjected to a stepwise regression and the same four factors emerged as important predictors of whether the subjects lived in the community or had returned to the MDC. These findings have important policy implications for the social integration of mentally handicapped people.

The next phase of the study involved an exploration of the quality of life of the subjects. Evaluation of quality of life is difficult, partly because of the lack of an agreed upon definition, and partly because of measurement problems. For the purposes of this report, quality of life was defined as:

> The discrepancy between what the individual has and what the individual wants in relation to a hierarchy of basic physical, psychological and social needs with the qualification that what the individual wants should be consistent with, and appropriate for, their current ability to function as an independent agent.

The theoretical framework for the evaluation of quality of life was based upon Maslow's hierarchy of needs which identifies, among several factors, that basic physical, psychological and social needs are fundamental to adequate human development. With respect to this study, physical needs were identified as adequate. Few of the subjects lived in situations characterized by an excess of material goods, but none lived in a state of deprivation either.

Generally, the psychological needs of the subjects could be described as reasonably good. Almost all lived in supportive environments which provided them with security and reasonable independence and freedom of choice. Few expressed dissatisfaction with their present status and few had aspirations for a substantially different way of life. These comments must not, of course, discount those who did aspire to a better life. Their inability to achieve their aspirations should not be interpreted as a criticism of the current arrangements. One aspect of the system that did appear to limit the progress subjects could make related to the lack of systematic training in community living skills, including such important aspects as interpersonal relations. The evidence clearly identifies the lack of social and community living skills as a major deficit of a substantial number of the subjects. This deficit, in turn, limits the ability of many to integrate into the community or to obtain and hold better jobs. Another potential problem area relates to the fact that the important role of "helper" is rarely carried out by anyone other than a paid professional. Although these professionals appear to manage this duty

well, it is a role that was expected to be carried out by family members, friends or volunteers. If, however, these groups are not carrying out this role, it places an additional burden on professionals who already work with very large caseloads and this additional and critical responsibility must be taken into account in calculating future workloads.

Social aspects of quality of life were also generally good. Many subjects reported having family with whom they visited regularly, and several friends who came from the same residences or workshops. Conspicuous by their absence were non-handicapped friends. Very few subjects reported non-handicapped friends and it is suspected that those who did were in fact classifying residential, workshop and community professionals as their non-handicapped friends. Similarly, very few subjects made systematic use of community resources other than a limited range of commercial enterprises.

Several global evaluations of quality of life were obtained and confirm the generally positive nature of the findings. Interviewer ratings of the quality of life of the subjects were very good. In addition, the subjects' own evaluations of their quality of life were very good. Overall, the quality of life of this sample of deinstitutionalized individuals was quite satisfactory.

## 9.3 CONCLUSIONS

The primary purpose of this study was to investigate the community adjustment of former residents of a Provincial institution for the

mentally handicapped. Community adjustment was defined as the degree of social integration and the quality of life of the subjects. Integration was investigated in relation to the use of community facilities, the work environment and the size and nature of the subjects' networks. Quality of life was investigated in terms of the adequacy of the physical, psychological and social aspects of the subjects' environment. A secondary purpose of the study was to investigate a smaller sample of former residents of the MDC who had been returned, and were currently living in the institution. The major purpose of this aspect of the study was to attempt to identify differences between the two samples and enable specific recommendations to be made for more effective preparation of institutional residents for community placement.

In considering the community adjustment of the subjects in this study, it is necessary to emphasize some specific features of the sample. With an average age of 42 years, the sample can be considered relatively mature. In addition, the sample includes a high proportion of individuals with multiple disabilities and noticeable stereotypic behaviours. Most of the sample had spent a large proportion of their life in the institution, with an average length of confinement of 13 years. These factors should be taken into account in evaluating the evidence relating to community integration.

Evaluation of the integration of the subjects in this sample is based in part on access to and use of community facilities. The findings indicate that most of the sample had the same access to community facilities as available to others in the same communities. Few

restrictions were placed on most individuals with regard to community access and independence of movement. Despite the fact that restrictions were not severe, the evidence is that few of the subjects made use of community facilities in any systematic way. Almost no-one participated in activities in the community other than those provided especially for the handicapped. One apparent cause of the limited use of community facilities was the lack of money to finance the cost of community activities. This lack of money is partly attributable to the very low wages paid in sheltered workshops. The lack of disposable income is further related to the great difficulty experienced by the subjects with regard to money management. These two factors appear to combine to place severe limitations on the ability of subjects to make use of available community resources.

Investigation of contact with neighbours revealed that some social interaction did occur but it was very limited. There was almost no desire on the part of the subjects to extend this contact or any expression of dissatisfaction with the current level of contact. In the reverse direction, non-handicapped neighbours expressed a clear acceptance of the presence of the mentally handicapped in the community, and showed a willingness for 'distant' social contact. However, there were reservations expressed by neighbours about the acceptance of closer social relationships, indicating that the acceptance of the physical presence of the mentally handicapped in the community was not an indication of willingness to integrate them into their own social circles.

Although a high proportion of the subjects reported they were working, most were working in some type of sheltered employment. The low wages paid in sheltered employment explains in part the lack of disposable income which limited the use of community resources. A similar circumstance exists regarding the living arrangements of the subjects in that almost all of the subjects lived in supervised residences provided for the mentally retarded. The working and living arrangements had been established, for most of the subjects, for a considerable period of time with little evidence of progress toward more open or integrated situations. An explanation of this could well be that the level of skill or ability exhibited by the subjects precluded their being more effectively integrated into community settings. It is beyond the scope of this report to debate whether integration precedes social competence or whether social competence leads to integration, but it does seem relevant to point out that an inevitable consequence of present policies is to confine the social network of these people to their co-residents and co-workers. The evidence clearly indicates that the subjects had almost no social contact with non-handicapped people outside of family and professionals in the social service system. Given the circumstances under which these people lived and worked, the lack of integration into the community can hardly be considered unusual.

In contrast to the lack of integration into the community, it should be emphasized that the subjects reported many friends among co-workers and co-residents and reported considerable satisfaction with these relationships. For almost all the subjects, companionship was provided

by those with whom they worked and lived, and most recreational activities were shared with this group of people. Interviewers' observations suggest that in both residences and workshops there was a sense of mutual interest and companionship among the subjects that apparently satisfied their affiliation needs.

Social integration may be categorized as external (community) integration and internal (residential) integration. The first category refers to the broad conception of community involving the neighbourhood and social setting in which the subjects lived. The second category consists of the residence and work place in which the subjects spent most of their time. The evidence gathered in this study strongly suggests that the subjects were not well integrated into the community in which they lived. The subjects were physically present in the community but did not actively participate in the social life of the community. By contrast, there is considerable evidence to suggest that the subjects were well integrated into a sub-community, consisting of fellow residents and workers. Within this environment the majority of the subjects found social and recreational activities and companionship. Thus, the inevitable conclusion is that the subjects were not well integrated into the various regions of the province in which they live, but they were well integrated into the social service system. It was this system that provided the residences where they lived and the workshops in which they were employed. The subjects have been relocated to the community but were not in any other sense integrated into the life of the community.

The expectations of those who so vigorously advocated

deinstitutionalization was that once living in the community, the mentally retarded who had been relocated would begin to integrate into the mainstream of society. However, the expectation that the mere relocation of residents from the institution into the community would result in integration was unrealistic. Deinstitutionalization is a complex issue and cannot be achieved without a systematic plan for delivery of all the necessary services, and adequate resources to ensure the plan can be implemented. Any attempts at this process which fail to recognize its complexity, or to provide adequate resources for its implementation, are almost certainly doomed to failure and are likely to create a climate of frustration that could damage future efforts to develop more appropriate living conditions for those with mental handicaps. The data from this study suggest that community integration has not occurred and furthermore that the expectations that subjects might have achieved integration, under existing conditions, were largely unrealistic.

The quality of life of the subjects was investigated in terms of the physical, psychological and social needs of individuals. The data provided evidence that the physical conditions for almost all individuals were adequate and that no individuals could be identified as living in unacceptable conditions. Indeed the conditions under which the subjects lived were representative of the conditions of non-handicapped people in similar economic circumstances. The evidence regarding psychological conditions is uneven. For example, the evidence is that the subjects themselves and observers believed the subjects were given freedom of

choice and independence in their residences and rated their quality of life as quite good. On the other hand, the amount of training and the type of training that was provided did not enable the subjects to improve substantially their opportunities for independent living in the community. The psychological environment in which the subjects lived and worked was supportive and provided guidance, and some training, but this was not sufficiently systematic or specifically directed toward the kind of independent living skills required by those in supervised residences. Similarly, although the work environment provided some training it was not geared toward training subjects in the type of social behaviour necessary for employment in the open market. In addition, the type of work provided in the workshops resulted in low economic returns with little development of marketable work skills. As a consequence, the residential and workshop environments provided a safe and secure environment for those with mental handicap, but little opportunity for them to increase their social or work skills as a means of obtaining greater social or economic independence.

The social needs of the subjects were encompassed by a small circle of family and their co-residents and co-workers. Although some subjects indicated they had some non-handicapped friends, the evidence suggests this was rare, and may have only implied a friendship with paid workers in the social service system. Nevertheless, the evidence clearly indicates that most subjects felt they had friendships which they enjoyed, and these friendships provided them with a sense of belonging and affiliation to a socially cohesive group.

The overall conclusion to be drawn from these data on quality of life must inevitably be a qualified one. In most respects, the quality of life as defined in this study was adequate to good. However, there were some areas, such as training, in which very little was being done in a determined and systematic way and with sufficient resources to have any substantial effect on the lives of these people. The question may be asked, to what extent does this factor detract from the overall rating of quality of life? The answer to this question depends on the perception one has of the role of the residences and workshops in the life of these people. Are they intended to serve as the training grounds for the intellectually handicapped to enable them to move to greater independence or are they the locations where these people are to live and work after having been placed in the community? It was not the intention of this study to answer this type of question, but rather to investigate the current conditions of those who had moved out of the institution, and report on their community adjustment as defined by the degree of integration into the community and their quality of life.

The evidence on community integration demonstrated quite strongly that these subjects were not well integrated into the social life in their neighbourhoods, but were quite well integrated into a somewhat closed community consisting of fellow residents and workers. The evidence regarding quality of life indicated that this ranged from adequate to good, but that there was a serious lack of systematic training, especially with regard to independent living skills.

One of the assumptions upon which this study was based was that full

social integration was a necessary condition of satisfactory community adjustment. The evidence derived from this study has now forced us to re-evaluate the usefulness of the original assumption with respect to those with intellectual handicap. There has been for many years an effective and vocal lobby advocating deinstitutionalization based upon the Principle of Normalization. Despite the many virtues stemming from this Principle, its advocates have frequently created an unrealistic expectation regarding the anticipated consequences. One of these expectations is that once people with mental handicaps have been relocated back into the community, they will become socially integrated and will participate fully in the life of the community. The evidence from this study suggests that this has not happened and will not happen without a dramatic increase in resources for work and social skill training. Even a dramatic increase in resources for this purpose may not be capable of achieving the kind of integration that many advocates have been suggesting. It appears unrealistic to think that mentally handicapped people can, or will want to be socially integrated with non-handicapped people. The evidence is that they are well satisfied with their current social network and this provides them with an appropriate and secure sense of community that may not be enhanced by relationships with non-handicapped people. In their present social network, the mentally handicapped have found a satisfying and fulfilling affiliation with people of similar abilities and interests. It appears that the current residential and work environments provide the opportunities for a range of social contacts that ensure most people can find friendship.

Smaller residential or work units would provide smaller social networks and perhaps reduce the opportunities for the development of friendships and result in more isolation and loneliness among this population.

There are, however, serious problems with the current arrangements that could be addressed with a minimum of additional resources and some administrative ingenuity. It was very evident from the descriptive data and the field notes that this sample of former residents of the Manitoba Development Centre was a very diverse group both in abilities and potential. As the analysis of these data proceeded it became increasingly apparent that no one residential solution would suffice to meet the variety of needs and wishes of such a diverse group. Our very firm conclusion, therefore, is that in all matters relevant to the provision of services for this population, a range of services must be provided which will accommodate the needs and abilities of the individuals being served. In practice this means the provision of a range of living options, from those that provide maximum support and supervision, to options that provide minimal support and no supervision. It appears to us that the very diverse needs of this sample could be met adequately only by the adoption of a policy which provides for a range of services which takes into account the degree of handicap, the degree of health and physical impairment and the functional abilities of those to be served. This policy would provide for more homogeneous populations in residences which would make the provision of appropriate training programs more practical and feasible.

This investigation of the predictors of social integration points to

the need for training programs which focus on independent living skills as a first priority and the management of behaviour problems as a second priority. The lack of socially appropriate behaviour in the community would appear to be one of the most serious problems facing the intellectually handicapped population. It is this lack of appropriate social behaviour which prevents greater integration into the community and greater use of available community resources. Concerns about the quality of life of these individuals should focus on the need for more training in this area rather than on integration with the non-handicapped population. If the mentally handicapped are isolated in the community, it is because they lack the social skills to enter more fully into the mainstream. To expect that the intellectually handicapped should first enter into the community, and there learn appropriate social behaviour is a position we totally reject for people who have been institutionalized for many years. There is no evidence to suggest that such learning has taken place in the past twenty years among this population, and no evidence that the situation is likely to change in the foreseeable future. It must be stressed at this point, that these remarks are intended to apply to those who have been institutionalized for several years and does not refer to those who have never resided in an institution. We make these recommendations regarding the range of community options with the full understanding that not all subjects in this study are capable of integration into the community, but in the belief that if a significant percentage are to achieve greater integration a considerable effort must be made to prepare them through a

systematic and long-term social skills training program.

The importance of consistency in the residential placement of the intellectually handicapped was evident from the strength of this factor as a predictor of social integration. It would appear that the initial placement of those discharged from the institution must be considered a crucial decision, and once made, changes should be contemplated only under exceptional circumstances. The placement decision should be based on such variables as the availability of social support in the community, but the training needs of the subjects must be considered the single most important factor. A variety of residential placements offering a range of training options would represent a major policy development in this field with important implications for the community adjustment of mentally handicapped people.

It should also be noted that there was strong support from the community for the right of the intellectually handicapped to live in the community and a good deal of acceptance by neighbours of "distant" social contacts with them. The evidence is clear that the climate is right for the social service system to prepare a comprehensive plan for the provision of a range of living options for the intellectually handicapped. It is our contention that the proposal for a range of living options providing a range of training programs is the most appropriate way to accommodate the diverse needs, and respond to the difficult problems of adjustment faced by this population. The proposition is not one that demands excessive financial resources. The proposal does require some additional allocation of resources but the

major requirement is for the adoption of a philosophy that allows for a variety of alternatives for the intellectually handicapped based on their functional ability and demonstrated needs. To this must be added a more effective organization of existing resources so that the recommended training programs could be effectively located in residential and work settings across the Province.

The evidence collected in this study suggests that the current functions of sheltered workshops need re-evaluation. Where the workshop provides employment to individuals who maintain reasonable rates of productivity, the work function is likely to provide an important source of pride and satisfaction for that individual. Where productivity is low, or where individual interest in participation is low, the sheltered workshop may need to adjust its goals to the growing awareness that work may not be the most appropriate activity for the more severely handicapped. Perhaps a more essential goal is to provide these people with a life-style based on the development of independent living skills and on active recreational activities as a means of maintaining physical and mental health. The recommendation does not imply the elimination of the existing workshop system but its transition to include a broader range of objectives than those that presently guide the operations of these facilities.

In conclusion, it should be stated that the limitations of the current policies to achieve greater community adjustment for former residents of the Manitoba Development Centre should not really be a surprise. The limitations cannot be attributed to individual factors,

but must be linked to a much broader analysis involving the motives for relocation and the adequacy of the planning process. This broader scope is necessary to be able to understand why the social services system has not been able to develop and deliver the type of services required by intellectually handicapped persons living in the community. The expectation that essentially all individuals could be relocated from a large Provincial institution such as the MDC into smaller regional residential facilities and that community adjustment would automatically follow was unrealistic. From the evidence of this study, it is our conviction that greater community adjustment of former residents of institutions for the mentally retarded can be attained, but an essential requirement for this process is the development of a comprehensive plan of services. This plan must be guided by a practical and realistic approach to the provision of a range of services for the intellectually handicapped. Community services should be based on an accurate appraisal of the needs and capabilities of the intellectually handicapped, and not on a philosophy that has pre-determined policy in isolation from the individual's ability to function independently in the community.

# APPENDIX

## Table A1

**DISTRIBUTION OF COMMUNITY SAMPLE BY SIZE OF RESIDENCE**

| Number of Co-residents | N | % |
|---|---|---|
| 0 | 11 | 12 |
| 1 | 6 | 7 |
| 2 - 3 | 17 | 19 |
| 4 - 5 | 15 | 17 |
| 6 - 7 | 17 | 18 |
| 8 - 11 | 17 | 18 |
| 12 or more | 4 | 4 |
| No response | 2 | 2 |
| Don't know | 2 | 2 |
| Total | 91 | 100 |

## Table A2

**SELF-ASSESSED INDEPENDENT LIVING SKILLS**

| Assessment | Wash Clothes | | Dress Self | | Keep Room | | Prepare Food | | Manage Money | |
|---|---|---|---|---|---|---|---|---|---|---|
| | N | % | N | % | N | % | N | % | N | % |
| Can't manage at all | 12 | 13 | 3 | 3 | 0 | 0 | 9 | 10 | 14 | 15 |
| Very poor at it | 3 | 3 | 2 | 2 | 3 | 3 | 7 | 8 | 8 | 9 |
| Fairly good at it | 13 | 14 | 19 | 21 | 21 | 23 | 21 | 23 | 15 | 17 |
| Very good at it | 22 | 24 | 55 | 60 | 52 | 57 | 19 | 21 | 17 | 19 |
| No response | 12 | 13 | 12 | 13 | 11 | 12 | 12 | 13 | 11 | 12 |
| Don't know | 1 | 1 | 0 | 0 | 1 | 1 | 0 | 0 | 2 | 2 |
| Done by someone else | 28 | 31 | 0 | 0 | 3 | 3 | 23 | 25 | 24 | 26 |
| Total | 91 | 100 | 91 | 100 | 91 | 100 | 91 | 100 | 91 | 100 |

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